University of Alberta

Self-reported health status of informal women caregivers of AIDS patients in Kinshasa, Democratic Republic of Congo

By

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Abstract

This study, done in Kinshasa, Democratic Republic of Congo from September to November 2002, is a combined quantitative and qualitative exploration focusing on the informal caregiving experience of women for husbands living with HIV/AIDS. Questionnaires were administered to the caregivers of 80 home care clients located in Bumbu zone. Three separate focus groups discussions were conducted with 6 home based care staff, 5 key informants and a sub-sample of 12 caregivers. Participants in the focus groups also took part in semi-structured interviews.

Findings have shown that, as informal caregivers for HIV/AIDS infected husbands, women face many difficulties and do not have much support. Consequently, the status of their own health is affected. The majority of them are experiencing more than one disease condition at the same time since they have started to care for their husbands. All of the participants were HIV/AIDS infected themselves, and are deeply concerned for their futures. In addition, they have children who have been diagnosed as being HIV/AIDS seropositive, but do not receive the treatment they need. The women have no choice but to stop working. This poses additional problems for acquiring food, medications and schooling for the children. Home care does help them. Unfortunately, the help available is not enough to cover their needs.

Several suggestions and recommendations have been formulated to alleviate the women's suffering and to improve their husband's condition of life. This study, by underlining the crucial role of the Congolese government in this matter, underscores the imperative for the general population in Congo to be educated about, and sensitised to, HIV/AIDS. This education and sensitization would both provide knowledge about the

infection, thereby dispelling myths and misconceptions, and descriptions of its demands and impact. The predicament of the caregiver would, therefore, become known and this knowledge would become the catalyst for precipitating action.

Key words: Stigma, Women as informal caregivers, Informal caregiving, HIV/AIDS, Health problems, Ostracism, Home care program

In memory of my loving father, **Pierre Nkosi Kaludieko**;

To

My mother **Julienne Kinzeka Mansila** for all you have done in my life.

My children **Carine**, **Tom** and **Reverence Matukala** for the sacrifices that you have been enduring because of my studies.

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Thomas Matukala Nkosi, M.Sc.

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Chapter 1: Introduction

Since the beginning of humankind, evolution has occurred. From the medical point of view for instance, early in history, infectious diseases were a rare occurrence. Several factors explain this situation including the absence of domesticated animals, and the nomadic life style adopted by humans during that period long ago in history. Progressively, as larger wild mammals became extinct, people relied on domesticated animals and turned to cultivating plants for food and sustenance. Consequently, they stopped leading a nomadic lifestyle and began living in close proximity with one another and also shared the same roof with their animals, and infectious disease emerged as a result of this close association (Desclaux, 1997).

The advent of disease was spread either by direct contact (through the air, polluted water, and food) or by indirect contact, such as through blood-sucking insect carriers of disease bearing mosquitoes, fleas and lice. Also during this era, widespread trading and the expansion of settlements commenced to meet the increased needs of the growing numbers of people in cities, townships and villages. The spread of disease escalated with these traders and as invading marauders and armies traveled from city-to-city and country-to-country (Desclaux, 1997). The world has since experienced many epidemics including influenza, cholera, salmonella, tuberculosis' infections, parasitic worms and now HIV/AIDS. Each one of these diseases has caused (and is still causing) serious implications for the global population.

With respect to the HIV/AIDS epidemic, scientists and health professionals face a huge challenge because of the profound impact that HIV/AIDS has had all over the world since its inception. HIV/AIDS triggers sympathy and passion in individuals who group together in solidarity to combat government, community and individual denial, and to offer support and care to people living with HIV and AIDS. On the other side, however, individuals can be stigmatized and ostracized by their loved ones, their family and their communities, and discriminated against by persons or by institutions (Aggleton, 2002).

The devastating effects of HIV/AIDS are not only undeniable but are also unforeseeable, as at this point, nothing indicates that an effective solution is at hand either now or in the near future. Given this scenario, supporting and caring for people with

HIV/AIDS poses many problems and will remain a challenge for long time. A discussion of the state of HIV/AIDS throughout the world and the context of caregiving for those who suffer from HIV/AIDS is presented in the following paragraphs.

1.1. Statement of the problem

1.1.1.HIV/AIDS in the World and in Africa

According to the literature, the Acquired Immune Deficiency Syndrome (AIDS) appears to be a relatively recent phenomenon. Scientists believed it was introduced into the human species in the late 1950s in Equatorial Africa. Reinhardt and others suggest the virus was first introduced in Congo, where millions of Africans were vaccinated with attenuated poliomyelitis virus strains, which were produced or cultured in kidney tissue obtained from monkeys (Reinhardt and Roberts, 1997).

Pieters also believes it is significant that the first cases of AIDS in Central Africa were reported in upper class Zairians (current Congolese) seeking medical treatment in Europe (Pieters, 1972). "Although mass vaccination programs have resulted in the eradication of a number of human infectious diseases, vaccine contamination has been a persistent concern. In particular, it is now known that early polio vaccines were contaminated with at least one monkey virus, SV 40. The transfer of monkey viruses to man via contaminated vaccines is particularly relevant to the AIDS, since the causative agent of AIDS, the Human Immunodeficiency Virus (HIV), is derived from a simian precursor virus" (Elswood and Striker, 1994, p. 349).

Despite the fact that the mechanism for the exact evolution of HIV from this vaccine remains to be determined, it has been hypothesized that the AIDS pandemic may have originated with a contaminated polio vaccine that was administered to inhabitants of Equatorial Africa between 1957 and 1959. Since its appearance in Equatorial Africa, AIDS has spread worldwide. "AIDS cases have been reported in countries throughout the world. Initial surveillance studies in Central Africa suggest an annual incidence of HIV infection of 550 to 1000 cases per million adults" (Quinn et al., 1986, p. 959).

Since there is no definitive cure for HIV/AIDS, the situation is rapidly deteriorating globally with increasing numbers of HIV infections. Prevention, therefore, still remains the best method for reducing the spread of HIV/AIDS. Some twenty years after the first

AIDS cases were detected in Congolese Africans living in Belgium, AIDS has become one of the most devastating diseases humankind has ever faced. Since the epidemic began, more than 60 million people have been infected with the virus. Worldwide, HIV/AIDS is the fourth largest cause of death. At the end of 2002, and as displayed in Table 1, an estimated 42 million people globally were living with HIV/AIDS (UNAIDS, 2002).

Table 1: Global HIV/AIDS prevalence rates, proportions and modes of transmission end of 2002 (UNAIDS, 2002)

Region	Epidemic started with HIV/AIDS	Adults and children living infected with HIV	Adults and children incidence rate (*)	Adult prevalence who are women	Main mode(s) of transmission (#) for adults living with HIV/AIDS
Sub-Saharan Africa	late '70s early '80s	29.4 million	3.5 million	8.8%	Hetero
North Africa & Middle East	late '80s	550 000	83 000	0.3%	Hetero, IDU
South & South-East Asia	late '80s	6.0 million	700 000	0.6%	Hetero, IDU
East Asia & Pacific	late '80s	1.2 million	270 000	0.1%	IDU, hetero, MSM
Latin America	late '70s early '80s	1.5 million	150 000	0.6%	MSM, IDU, hetero
Caribbean	late '70s early '80s	440 000	60 000	2.4%	Hetero, MSM
Eastern Europe & Central Asia	early '90s	1.2 million	250 000	0.6%	IDU
Western Europe	late '70s early '80s	570 000	30 000	0.3%	MSM, IDU
North America	late '70s early '80s	980 000	45 000	0.6%	MSM, IDU, hetero
Australia & New Zealand	late '70s early '80s	15 000	500	0.1%	MSM
TOTAL		**42 million**	**5 million**	**1.2%**	

* The proportion of adults (15 to 49 years of age) living with HIV/AIDS in 2002, using 2002 population numbers.
# Hetero (heterosexual transmission), IDU (transmission through injecting drug use), MSM (sexual transmission among men who have sex with men).

According to UNAIDS, the HIV/AIDS epidemic seems to be on the rise again in 'high-income' countries within North America, Western Europe and Australia, as well, where approximately 76,000 people acquired HIV in the year 2002, bringing the total number of people living with HIV/AIDS to 1.6 million in this part of the world

(UNAIDS, 2002). In the year 2002 alone, the epidemic claimed the lives of an estimated 23,000 people in the West. One must recognize that in these developed countries much has been accomplished in terms of both prevention and treatment, but we still do not have a real cure for AIDS.

At best, preventative actions such as safe practice, voluntary testing or participation in HIV support groups, treatment and care programs in the western world offer some respite in the fight against HIV/AIDS. Recent advances in treatment and care in developed countries have not been consistently matched with enough progress in regard to prevention of HIV/AIDS. On the contrary, new evidence of rising HIV infection rates in these countries has emerged clearly demonstrating some failure of the preventive strategies. "It seems no longer sufficient to see prevention as the transfer of knowledge from professionals to the population" (Desclaux, 1997, p. 129). Unsafe sexual practices reflected in outbreaks of sexually transmitted infections and widespread injection drug use are reasons for the increased spread of HIV/AIDS in many developed countries. This evidence also shows that HIV/AIDS is shifting more towards marginalized communities within developed countries (UNAIDS, 2001).

Eastern Europe and Central Asia are regions that are experiencing the world's fastest-growing HIV/AIDS epidemic in term of number of cases. In the past year there were an estimated 250,000 new infections, bringing the number of people who became infected with HIV/AIDS in Eastern Europe to 1.2 million. In Latin America and the Caribbean, an estimated 1.9 million adults and children are living with HIV/AIDS. These statistics include an estimated 210,000 people who acquired the virus in 2002. Almost 1 million people in Asia and the Pacific became infected with HIV in 2002, increasing the number of people now living with the virus to 7.2 million. A further 490,000 people are estimated to have died of AIDS in the past year in Asia and the Pacific (UNAIDS, 2002).

In the Middle East and North Africa, available data point to increasing HIV infection rates, with an estimated 83,000 people having acquired the virus in 2002. The total estimated number of people living with HIV/AIDS now stands at 550, 000. The epidemic claimed approximately 37,000 lives in 2002 (UNAIDS, 2002).

Sub-Saharan Africa is considered as the worst affected region where AIDS is now the leading cause of death killing 2.4 million people in 2002. Approximately 3.5 million

new infections occurred in 2002, revealing that 29.4 million Africans now live infected with the virus. The majority are young adults. Ten million young people aged 15-24 and almost 3 million children under the age of 15 are living with HIV/AIDS. Most of them do not know that they carry the virus. Some still do not know the facts about HIV, or how to protect themselves against becoming infected.

Since adequate treatment and care do not exist, only a tiny fraction of the millions of Africans in need of antiretroviral treatment are receiving it, and many millions more are not receiving treatments necessary for opportunistic infections. Most of those currently living with HIV/AIDS will not survive the next decade (UNAIDS, 2002). Recent antenatal clinic data show that in several parts of southern Africa, for example Botswana, the prevalence rates of HIV infection amongst pregnant women is well over 30% (Ndaba-Mbata, 2000). In West Africa, several countries are experiencing serious HIV/AIDS epidemics with adult HIV prevalence exceeding 25% (UNAIDS, 2002). In Democratic Republic of Congo, the situation remains dramatically serious, with high HIV infection rates and still increasing HIV prevalence in the sexually active population and in newborns. Women and girls, who are commonly discriminated against in terms of access to education, employment, credit, health care, land and inheritance, are more affected than men and boys. Meanwhile, ignorance about sexual and reproductive health and HIV/AIDS is still widespread across the entire territory (urban or rural) of Congo.

1.1.2 HIV/AIDS Caregiving in the World and in Africa

Even though the next chapter will investigate and provide an in-depth review of literature concerning the caregivers of those infected with HIV/AIDS, this section will also briefly state why HIV/AIDS caregiving remains a continuing issue of concern. While the prevalence of HIV continually increases, giving evidence of the failure of many preventive strategies, medical breakthroughs have prolonged the lives of HIV infected persons. Consequently, throughout the world the number of persons living with HIV/AIDS continues to increase and the complicated regimens of treatments and the physical effects of both treatment and disease require more and more support and caregiving by family members. Supporting and caring for people living with HIV/AIDS

depends on many factors: the family income, the family cohesion, and the country of residence, just to name a few.

With regard to the country of residence, UNAIDS (2002) reported that several changes have emerged in recent years in high-income countries where the health care system is well established. Depending upon the country of residence, some people living with HIV/AIDS are well taken care of, and the introduction of antiretroviral therapy since 1995/1996 has dramatically reduced HIV/AIDS-related mortality. Both counselling and prevention services are offered, although they could be provided on a larger scale (UNAIDS, 2002).

In the continents of South America and Africa, where extended families provide a safety net for individuals in terms of need, the role of families is essential in patient assistance due to the inability of the health care system to deal with all AIDS patients. Caregiving by family members is imperative in developing countries because hospitals usually are over crowded and cannot be reached by many patients. Financial issues, the limited capacity of home care, and the stigmatization of AIDS patients are also reasons for caregiving by family members. The study considers an informal caregiver as the woman who has the primary responsibility for looking after her HIV/AIDS infected husband.

Some published evidence exists in the literature on how the family deals with a family member who is living with AIDS/HIV (Land and Hudson, 2002). This evidence suggests that there is a huge need for more support for informal caregivers, especially for women who do most of the care in the home (de Figueiro and Turato, 2001). Except for underlining that family members need to receive assistance and training from nurses in order to be able to follow a care plan for the AIDS patient at home, none of these studies addresses the needs of the caregivers. It has yet to be stated exactly how much help families' need, when they need the help and how to administer that help.

Additionally, these studies fail to mention how caring for people living with HIV/AIDS can affect the health status of the caregivers, a topic this study has chosen to focus upon. This investigation also considers women in poor areas.

1.2. Purpose

The purpose of this study is to assess whether the additional caregiving burden imposed on the women caring for family members with HIV/AIDS in the Democratic Republic of Congo impacts negatively on their health. Assessing caregiver burden and how it might adversely affect health status, is especially relevant to the Democratic Republic of Congo, as this area remains a high HIV prevalence country.

Caregiver burden can be defined not only as the implications of caregiving on family relationships and crisis planning, but also in terms of the impact on personal, physical, emotional and psychological health, the amount of help required and the financial costs of caregiving. Caregiver burden will also be understood as a result of stress factors, personal activity limitations (Reinhard, 1994), as well as other subjective factors such as caregiver perception (Semlyen et al., 1998) and coping ability (Sander et al., 1997).

In particular, this study seeks to accomplish the following: 1) Describe the problems faced by women as informal caregivers for their husbands living with HIV/AIDS; 2) Identify the problems, which influence women health status and how; and 3) State how women solve these health issues.

As the Democratic Republic of Congo is a high HIV prevalence country, answering these questions is important and will contribute to new knowledge about women as caregivers of AIDS patients. This information is crucial for policy formulation, as well as planning and resource allocation for new programs aimed at supporting women as caregivers of family members who are suffering from AIDS. This study will also benefit the HIV/AIDS control program in Kinshasa in the following ways:

- Drawing attention to the caregiving burden of women who are major care providers for AIDS patients in Kinshasa;
- Providing detailed information for medical and social support programs for women in Democratic Republic of Congo;
- Improving home-based care of AIDS patients in Kinshasa through caregiver support;

- Assessing the impact of HIV/AIDS at the household level, especially on women caregivers;
- Using proven and valid Canadian tools for the benefit of a developing country.

The upcoming chapter provides background information on Congo and Kinshasa, which will allow us to situate the HIV/AIDS problems in the Congolese context in order to better grasp the societal situation, and seek to solve the dilemma.

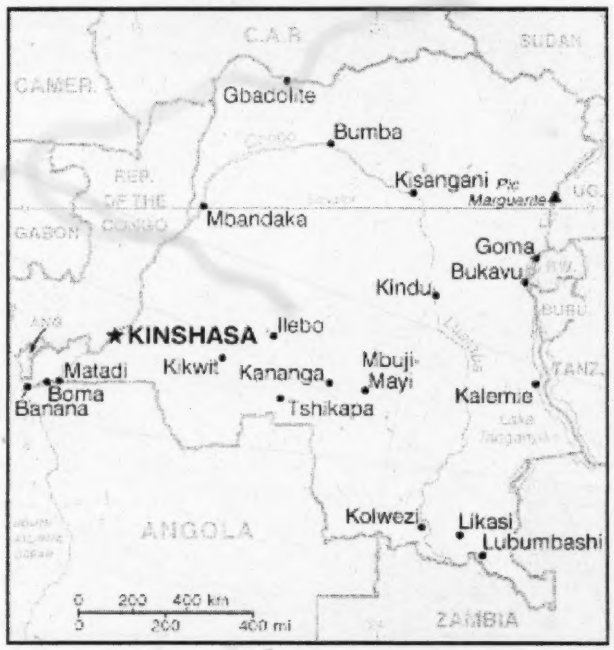
Chapter 2: Background information

The following chapter is composed of two main sections. The first section is a description of the Democratic Republic of Congo, whereas the second section will concentrate upon Kinshasa background information.

2.1. Democratic Republic of Congo background information

The Democratic Republic of Congo (a former Belgian colony) is located in the centre of the African continent (see Map 1. below), and is bordered to the South by Angola, which shares a boundary with the Cabinda Province and Zambia. The eastern side of the country borders upon Tanzania, Burundi, Rwanda and Uganda. The northern border rests beside Sudan and the Central African Republic. Finally, Republic of the Congo, a former French colony borders the Democratic Republic of Congo on the west.

Map 1: The Democratic Republic of Congo



The World Factbook, 2002

Slightly less than one-fourth the size of the United States, the Democratic Republic of Congo extends across a surface of 2,345,410 sq km, with 77,810 sq km of water and 2,267,600 sq km of land. Agricultural land use in Congo is only 2.96% of

arable land, with 0.52% for permanent crops (The World Factbook, 2002). The lowest point of Congo rests at the Atlantic Ocean at 0 m, while its highest point is the Pic Marguerite on Mont Ngaliema, also known as Mount Stanley, at 5,110 m. The Democratic Republic of Congo is divided into 10 provinces: (Bandundu, Bas-Congo, Equateur, Kasai-Occidental, Kasai-Oriental, Katanga, Maniema, Nord-Kivu, Orientale, Sud-Kivu). The capital city is Kinshasa.

According to the World Factbook (2000), the Democratic Republic of Congo has a tropical climate: hot and humid in equatorial river basin, cooler and drier in southern highlands, and cooler and wetter in eastern highlands (north of Equator). One distinguishes two seasons in Congo: wet season, which goes from September to April, and a dry season from May to August.

2.1.1. History and Politics

With the advent of the violent imposition of Belgian colonial rule in 1885, the Democratic Republic of Congo was established as a personal fiefdom for King Leopold II of Belgium, and called the Congo Free State. After 75 years of colonial rule, the Belgians left abruptly, relinquishing the political rights to the people of Congo in June 1960. However, economic foundations that could have allowed the country to flourish were not in place. From 1960 to 1965, the Republic Democratic of Congo was ruled under the Belgium Constitution with Kasa-Vubu as the President. In 1965, after the first rebellion, Mobutu took power through a coup d'état. Congo had its first constitution on the 24 June 1967. In 1971, The Republic Democratic of Congo (RDC) changed its name and became Zaire (Veraghaen, 1974).

The Zaire Constitution was amended in August 1974, and following another review in February of 1978 and again in April of 1990. With the winds of democracy sweeping the nation, the Congo had a transitional constitution promulgated in April 1994. Political evolution in Congo has been dictated by the attitude of the United States since the middle of the last century: "U.S. policy toward Mobutu was rationalized on the grounds of fighting 'communism' and Soviet influence in Africa, but the U.S. was clearly more concerned with securing its own interests in the region than helping foster a stable, secure, and peaceful future for the people of Central Africa. Lying at the centre of the

continent, Zaire could provide the U.S. with access to important resources, transportation routes, and political favours. Over the years, U.S. rhetoric changed slightly, placing greater emphasis on democratic reform of the regime and increased attention to human rights, but in reality policy continued to focus on promoting narrowly defined U.S. economic and strategic interests" (Hartung and Moix, 2000, p. 23).

In May 1997, Laurent Kabila came to power by toppling Marshall Mobutu with the aid of Rwanda, Uganda, Angola, Burundi and Eritrea. He changed the name of the country from Zaïre to Democratic Republic of Congo (DRC) and suspended the Constitution. On January 16, 2001 Laurent Kabila was assassinated and his son Joseph Kabila was sworn in as the new President of the DRC. He became both the Chief of State, as well as the head of government. Since then, there have been many internal conflicts where various sides have been supported from various neighbours.

2.1.2. Socio-Cultural situation

Congo is a cultural mosaic. It has almost 430 tribes and over 200 African ethnic groups of which the majority are Bantu. The distribution of the various ethnic groups is uneven. The five largest ethnic groups are: Kongo, Kwilu-Kwango, Ubangi, Mongo and Luba (Matukala, 1996). Each ethnic group is specifically organized and ruled by its own values and customs, although there are many similarities between the groups, for example, the importance accorded to marriage and procreation.

According to Sala-Diakanda (1980), for the Congolese people, marriage is an essential function of the social life. Among other things, marriage conditions and influences the new alliances between groups, and married couples do not constitute an independent and self-sufficient rightful group in the society. The principal objective of marriage is procreation, which is given great emphasis. Births are celebrated with ostentation. After each delivery, a woman is given a postnatal sabbatical and does not return to her family for at least three months. In Kinshasa, spouses sleep in different rooms. In general, the man leaves the bedroom. Breast-feeding is obligatory, and lasts for up to 18 months.

During this time men, who culturally are allowed to have more than one wife or sexual partner, remain sexually active. In fact, promiscuity (defined as having sexual

relationship with many partners) and polygamy (a culturally legitimate matrimonial union where a man has more than one wife) are an integral part of Congolese traditional culture. Promiscuity in Congo occurs both premaritally and postmaritally, and is practiced in both rural and in urban areas.

Many religions are present in Congo: Roman Catholic 50%, Protestant 20%, Kimbanguist 10%, Muslim 10%, other syncretic sects and indigenous beliefs totalling 10% (Congolese National Institute of Statistics, 2001 and 2002). The official language, the language of administration, in Congo is French. As well, Congo has a number of patois languages as well as four national languages (Lingala, Kikongo, Kiswahili or Swahili and Tshiluba).

Congolese people are not well educated and the illiteracy rate rests at 77.3%. This means only 22.7% of people age 15 and over can read and write in French, Lingala, Kikongo, Swahili or Tshiluba. By gender, the illiteracy rate is 86.6% for women and 67.7% for men (Congolese National Institute of Statistics, 2001 and 2002).

2.1.3. Economic context

The Democratic Republic of Congo is a nation endowed with vast potential wealth in cobalt, copper, cadmium, petroleum, industrial and gem diamonds, gold, silver, zinc, manganese, tin, germanium, uranium, radium, bauxite, iron ore, coal, hydropower, and timber. Despite these resources, the economy has drastically declined since the mid-1980's, probably as consequence of the "zairianisation" effected by president Mobutu in 1973. Zairianisation consisted of confiscating all of the foreign business and giving it to Zairians despite their lack of knowledge and experience in various fields of business.

War, which returned in August of 1998, has also dramatically reduced national output and government revenue, and has increased external debt. Foreign businesses have curtailed operations due to uncertainty resulting from the conflict, lack of infrastructure, and the difficult operating environment (The World Factbook, 2002). War has intensified the impact of such basic problems as an uncertain legal framework, corruption, raging inflation, and lack of openness in government economic policy and financial operations. A number of IMF and World Bank missions have met with the government to help it develop a coherent economic plan, and President Kabila has begun implementing

reforms. In 2002, the RDC GDP rate (real growth rate) was estimated at -4%. In Congo the main agricultural products include coffee, sugar, palm oil, rubber, tea, quinine, cassava (tapioca), palm oil, bananas, root crops, corn, fruits and wood products (Congolese Minister of Agriculture, 2002).

2.1.4. Demography and Basic Health indicators

With a growth rate estimated at 3% a year, the Democratic Republic of Congo's population rests at approximately 60,000,000 people. The population structure is young: 48.2% are under the age of 14 years, 49.3% are between 15 and 64 years old and 2.5% are 65 years and over. Table 2 below shows how the Congolese population is structured by age and gender. There are more females (50.6%) than males (49.4%) in Congo.

Table 2: Structure of the Congolese population by age and gender

Ages (in years)	Males	Females	Total
Under 19	28.5 %	28.5%	57.0%
20-59	18.7%	20.2%	38.2%
60 and over	2.25%	1.90%	4.15%
Total	49.4%	50.6%	100

Source: Calculated from scientific census of 1984, Congolese National Institute of Statistics (2002)

The Congolese birth and death rates are respectively 45.55 births per 1,000 population and 14.93 deaths per 1,000 population (Congolese National Institute of Statistics, 2002). The gender ratio at birth is 1.03 males per 1 female and the total fertility rate is about 6.7 children born per woman. The infant mortality rate is estimated at 98 deaths per 1,000 live births. This leads to a lower life expectancy at birth, which is estimated at 49.13 years (51.1 years for female and 47.2 years for male).

The Democratic Republic of Congo is referred to as a country of emigration (Congolese Minister of Planning, 2002). Its Net Migration Rate was approximately -2.75 migrant(s)/1,000 population in 2002. This is one of the consequences of the civil war in the eastern part of the country, where conflict continues between the Congolese government and Uganda- and Rwanda-backed Congolese rebels.

2.1.5. HIV and current related issues

In the Democratic Republic of Congo the first cases of HIV/AIDS were reported to the Ministry of Health in 1983. Since then, more than a million people have died of AIDS, and HIV/AIDS has continued to spread to become a major health and social issue. Almost 25% of the sexually active population are HIV positive. People between the age of 20 and 39 years have the highest level of HIV infection rates (Congolese Minister of Social Affair and Public Health, 2002).

The subordinate position of women in Congolese society makes it difficult for women to be protected or to protect themselves. Women tend to be infected at a younger age than men, 15-25 years in women and 25-35 years in men. Given this, the average age of men with HIV/AIDS is 35 years and the average age of women with HIV/AIDS is 25 years. Girls have significantly higher infection rates than boys and the highest HIV prevalence is found among women young 20-24 years of age. In 2002, AIDS claimed about 20,000 Congolese lives (Congolese National Institute of Statistics, 2002).

Sexually transmitted diseases (STDs) also facilitate the transmission of HIV. In Congo, HIV sero-prevalence amongst people infected with STDs is over 60%. There is a trend for men to seek younger female sexual partners because of a fairly widespread misconception that sex with a virgin will "cleanse" an infected person of their HIV/AIDS infection. This has resulted in a rate of growing infection amongst teenage (and younger) girls.

It is believed that actual number of persons with HIV/AIDS in Congo is much higher than the reported figures due to a poor infrastructure that is the result of the current war. Additionally, it is not possible to obtain an accurate count of persons with HIV/AIDS since HIV/AIDS is still considered as a disease that stigmatizes both the patient and the family members. Therefore, many HIV/AIDS infections are not formally reported to the health authorities.

Family members of HIV/AIDS patients usually express fear of loss, shock, and disbelief at the diagnosis. Persons with AIDS and their families fear rejection from those outside the household due to the perceived stigma associated with AIDS. With declining physical condition, HIV/AIDS infected people and their families in Congo prefer avoiding outside contacts. More often the Congolese HIV/AIDS patients choose to

reduce their mobility and stop working. This results in decreasing available economic resources for the patients and their families.

The spread of AIDS in the DRC has been attributed to poverty, lack of education, and the ongoing-armed conflict although it is potentially one of the richest countries in the world. Congo possesses vast reserves of natural resources, yet years of government mismanagement and corruption have left the country in ruins. Unemployment runs at more than 60 percent. A large number of men who cannot find work often abandon their families, leaving their wives to care for the children. The lack of a government social welfare system and the lack of work give these women little choice but to resort to prostitution in order to support their families which also promotes the transmission of HIV/AIDS.

As in the majority of African countries, the AIDS epidemic in the DRC has also been exacerbated by lack of education. Many people do not have enough information about the disease, and because the Congolese culture does not encourage discussion about sex, it is difficult, as a consequence, for people to be educated about AIDS. A large number of people, especially in the religious communities, think of the epidemic as God's judgement upon mankind. Others simply think of AIDS as a form of witchcraft. That is why HIV/AIDS calls also for nurses to go beyond the strict Western-based bio-medical model before being able to help and understand patients who come from Congolese or from African culture background (van Dyk, 2001).

According to traditional Congolese perceptions of the causes of illness in general and of HIV/AIDS specifically, God, ancestors, witches, magic, supernatural powers, breach of taboos or loss of ancestral protection, etc. intervene in the morbidity process. Congolese believe that myriad driving forces have a profound effect on the spread of the HIV/AIDS. The outbreak of the current armed conflict in the Democratic Republic of Congo has also contributed to the spread of AIDS. According to members of the Congolese civil society, many of the soldiers sent into combat test positive for HIV (Mulegwa, 2000).

2.2. Kinshasa background information

2.2.1. Population and Culture

Kinshasa, capital of Democratic Republic of Congo, has an area of 9,965 sq km and is the most populous city in Congo. Kinshasa's population has increased dramatically since the 1940s: totalling only 400,000 in 1960, increasing to an estimated 4.4 million in 1996 and 8.1 million in 2002 (Congolese National Institute of Statistics, 2002). Kinshasa's population is generally young, with 58% of people less than 20 years of age. The increase in city residents is due to a combination of many factors including high birth rate, a tendency for investment and government spending to concentrate in the capital, Kinshasa's reputation as a place of wealth, power and culture; and the pauperization of the Congo's rural areas. The city has been the destination of hundreds of thousands of migrants from other parts of the Democratic Republic of Congo.

Five main ethnic groups are represented in Kinshasa: Bakongo, Kwilu-kwango, Mongo, Luba and Ubangi (Matukala, 1996). Even though Kinshasa is located in the area traditionally dominated by the Bakongo ethnic group, Kikongo (the language of the Bakongo) has largely been supplemented by Lingala, which serves as a common language for the city's diverse population. Kinshasa is the location where the Roman Catholic archbishop resides. It is also the headquarters of the Baptist Church and of Kimbanguism, a Congolese sect that fuses Christianity with traditional African religion and is particularly strong in the region (Tambashe and Shapiro, 1991). Kinshasa is a centre of traditional and modern African culture, and the city's artists are noted for their sculpture, oil painting, woodcarving, and jewellery making. The city is also known throughout Africa for its lively Congolese music scene.

Despite having a fair number of schools and other educational and cultural facilities, Kinshasa has a low literacy rate of 20%. Schools are generally poor, there are not enough materials, and teachers are insufficiently paid, and few students receive an education beyond the primary level. The city has several large public and private health institutions (hospitals, clinics, and other medical facilities). However, most Congolese cannot afford care at these institutions, and the extremely humid climate and poor sanitation of the city foster disease. The city remains both poorly urbanized and electrified. Throughout the city the running water is not pure.

Plagued by high rates of violent crime and theft, Kinshasa has been the scene of recurrent riots and looting, including incidents perpetrated by the seldom-paid and undisciplined Congolese army during the 1990s. Environmental problems include deforestation of a broad green belt around the city, and uncontrolled pollution from residences and businesses (Tambashe and Shapiro, 1991).

2.2.2. Public Health and HIV

The health data, produced in December 2002 by the Social Affairs and Public Heath Ministry of the Democratic Republic of Congo, indicate that the public health situation in Kinshasa is increasingly grim. Many Kinshasa inhabitants suffer from the main tropical killers of typhoid fewer and bacillary dysentery. The most frequent deadly disease however continues to be malaria, as it is on the African continent at large. Malaria control and prevention has been problematic, given the city's environmental health situation of poor water and sanitation. Other tropical diseases are also observed in Kinshasa, although on a lesser scale. Cholera cases prevail, but have dropped. Measles is also observed, but the city's child vaccination program has had significant positive results. There have also been reports of a possible case of Ebola haemorrhagic fever (Veka and Hennig, 2002).

HIV/AIDS, so far, has not been given the attention it deserves in Congo-Kinshasa. Worse, the awareness of Kinshasa inhabitants about HIV/AIDS is dramatically low due to the high level of illiteracy. For many reasons, such as stigma, financial issues, the poverty of the health care system, the exact numbers of people affected by the virus remains unknown. The HIV/AIDS rate in Kinshasa is estimated to be relatively high. Of its 8 million inhabitants, 30% of the sexually active and 20% of newborns are reported to be HIV positive in the city of Kinshasa (Congolese National Institute of Statistics, 2002).

2.2.3. Strategies for fighting against HIV: the case of Sacome+ in Bumbu

In facing the danger that HIV/AIDS represents, many actions have been considered and enacted. Those actions include international, national and local strategies. At the international level, partnerships have been developed between the Congolese government and foreign governments and/or organizations such as UNAIDS, USAID,

and WHO. At the national level, the government has established health zones to improve public health delivery and fight against HIV/AIDS.

A National Program for Fight against the HIV/AIDS has been created. The National AIDS Coordination Program is situated in the Ministry of Health and Social Affairs. Its role, essentially, is to coordinate the National HIV/AIDS activities. Recent activities included the development and provision of voluntary counselling and testing services, HIV/AIDS national policy development, promotion of comprehensive training and treatment protocols for sexually transmitted infections, HIV surveillance activities and overall HIV/AIDS coordination. However, the allocated budget has been inadequate to make any meaningful impact on the epidemic.

Locally, many non-governmental organizations have been created as a response to the HIV/AIDS crisis and the problems it causes. One of those non-governmental organizations is the Sanitary Committee for Men plus (Sacome+) in the zone of Bumbu, which was implemented in 1994. All the eighty participants of this study are caregivers of the Sacome+ clients.

Sacome+ seeks to identify and protect the human dignity of men living with HIV/AIDS and their families, to raise the awareness of the population (especially of those at risk of infection) in Kinshasa, and to prevent the spread of the virus. The Sacome+ also tries to increase access to information, counselling, psychosocial assistance, and home care for men living with HIV/AIDS and their families. Sacome+ does this through the home-based care program, financial and material aid, psychosocial support, anti-stigma and anti-discrimination campaigns, behaviour change and education.

Structurally, Sacome+ has two divisions under the General Directorate: The Social Actions and Health Division, and the Communicating for Behaviour Changes Division. Beside the members of the General Directorate, health professionals (doctors, nurses and social workers) and twelve volunteer members compose the Sacome+. The partners of Sacome+ are The National Program of fighting against the HIV/AIDS, the AIDS Forum, The Congolese network of people living with HIV/AIDS, the Congolese Red-Cross, the Women plus foundation, UNAIDS and WHO.

Sacome+'s home-based care program for people living with HIV/AIDS and their families mostly relies on unpaid volunteers with limited training. The Sacome+ activities

include home visits and surveys, home-based counselling, psychological support group meetings, nursing care or medical assistance and delivery of supplies such as laboratory tests, basic treatments, help with hospitalization fees, referrals, as well as psychosocial counselling, pastoral support, welfare assistance (funeral organization and costs) and legal aid (related to inheritance). In terms of preventive activities, Sacome+ has organized training and awareness-raising sessions throughout Kinshasa.

Concretely, Sacome+ offers a wide range of services and voluntary counselling and testing services to people living with HIV/AIDS and their families. These include the acceptance of seropositive status, which facilitates behaviour change; the early management of opportunistic infections; the possibility of entry into a treatment program with antiretroviral agents, the reduction in mother to child transmission; training for family caregivers, social/ psychological/peer support; planning a future for orphans and normalizing HIV/AIDS. Sacome+ organises normally two visits for each family every month. The number of these visits, however, increases with the gravity of the case or with the increased need of the patient and his family. People infected with HIV/AIDS and their families may also visit the Sacome+ centre when they wish.

Individual pre-test counselling is given to women with young children under 6 years of age whose husbands are HIV/AIDS infected, but this is done on a volunteer basis and when nurses are available to provide this service. When a patient tests HIV positive, an on-going counselling service is immediately offered. HIV/AIDS awareness campaigns are carried out regularly, as well as HIV/AIDS education throughout the city of Kinshasa. Care of orphans is offered in supplementary food and clothing programs for those less than 5 years of age, but the programmes are not adequate.

Ostensibly Sacome+ services and care are provided without charge and irrespective of the social and economic situation of the client. In reality, people pay the equivalent of five Canadian dollars when they can for every visit. Sacome+ usually relies on donations and funding from a multitude of donors. These donors include the Bumbu municipality, provincial authority or national government, as well as individuals and Sacome+ members' contributions. The staff, nurses and social workers, are trained to render a wonderful service that enables HIV/AIDS patients and their families to cope more effectively with devastating circumstances.

Since its inception, Sacome+ has helped about 500 people living with HIV/AIDS. Many of them have since died or moved to rural areas due to the stigma of the disease. Currently, Sacome+ has approximately 300 clients infected with HIV/AIDS. Sacome+ identifies HIV/AIDS people through a "social survey system" which consists of asking friends or neighbours if they are aware of a suspected HIV/AIDS case. Once Sacome+ is informed of a probable case, the group tries to engage the individual and convince him to have a test. When the outcome of the test is positive, Sacome+ begins to help the HIV/AIDS infected person and his family members.

Chapter 3: Literature review and theoretical orientation

This chapter has three sections. The first section describes what we know about informal HIV/AIDS caregiving through literature, including the relationship between the patient and the caregiver, and the impact of caregiving on the health condition of the caregiver. The second section describes what has been written on stigma and discrimination that HIV/AIDS patients and their families suffer from daily. The third and last section reviews the literature related to the conceptual framework, which focuses primarily on the relationship between social cohesion and health status.

3.1. Informal HIV/AIDS caregiving in different contexts

Whatever the context and the health condition of patients may be, informal caregiving for an HIV/AIDS person involves at least two people: the HIV/AIDS patient and the informal caregiver(s). Informal caregivers of people with AIDS (PWAs) provide practical help and nursing care at home. They are often the lovers, spouses, friends, or family of someone with AIDS and are not necessarily professional care providers. "Caregivers provide practical support such as shopping, housekeeping, and transportation to clinics, as well as more basic assistance such as help with bathing, going to the bathroom, and feeding. As symptoms worsen, caregivers are also likely to take on more clinical roles such as keeping track of medications, giving injections, inserting catheters, and cleaning wounds" (Folkman, Chesney and Christopher-Richards, 1994, p. 37).

This study focuses on wives who provides caregiving to their husbands, who are suffering from clinical AIDS. "The bottom line of family caregiving is a relationship between two people. Usually, they know each other well before the onset of AIDS. However, these people often find that the new roles of caregiver and care-receiver have thrust them into uncharted territory. They must understand each other on new terms, rethinking their roles and renegotiating the give-and-take of daily life. And, since AIDS can change people in unpredictable ways, caregivers who met the person with AIDS before the illness began must also renegotiate how they will relate to each other from day to day" (Brown and Powell-Cope, 1992, p. 1).

A number of major issues affect the role of the family HIV/AIDS caregivers. AIDS is prevalent in both young and middle-aged people, and one in every four new HIV

infections occurs in young people under the age of 22 (Rosenberg, Biggar and Goedert, 1994). "Caregivers, also, are often in their 20s, 30s and 40s. At that age most people are traditionally building relationships and developing careers, not caring for sick people or preparing for the loss of their partner. The stress involved in this "off-time" caregiving can be enormous" (Folkman, Chesney and Christopher-Richards, 1994, p. 37). Unlike professional care providers, informal caregivers are often on call 24 hours a day and are not protected by a limited workday or professional distance. Many informal caregivers have never cared for a seriously ill person, nor have they seen someone die. "Also, caregivers must learn skills such as how to give shots or insert catheters, often under extremely stressful circumstances" (Folkman, Chesney and Christopher-Richards, 1994, p. 39).

On the other hand, a lot of informal caregivers for people living with HIV/AIDS are also sexual partners for the people they care for, which constitutes a risk for HIV infection. For HIV-positive informal caregivers, disease progression leads to the loss of their partner as well as to the change of their own health status. Caregiving also raises the question of who will care for the informal affected caregivers when they become ill themselves? This type of question makes their lives very stressful. Informal caregivers may experience numbness, compassion, fatigue, or burnout from losing multiple friends and loved ones to AIDS, or from caring for someone who has been ill for a very long time (Poindexter, 1998). In many communities both the fear and stigma surrounding HIV disease remain a strong influence (Cohen and Syme, 1985).

Often, the informal caregiver is forced to make a special effort and encounter new experiences in order to take on so many critical responsibilities. Very few people understand what they are up against as they begin caregiving. On the contrary, people are likely to form tentative images of themselves as family caregivers and of the journey they're about to take. They consider their human resources as sufficient enough, and they take on the role (D'cruz, 1998). Later on, when they face unforeseeable duties and hardships, they decide to reassess their abilities. This, in turn, has a significant impact on their efforts, and on the condition of health of the person with AIDS.

The Fifth Annual Conference on Social Work and HIV/AIDS, held in San Francisco in June 1993 focused on the "Issues of Caregiving for the HIV/AIDS

Caregiver" and concluded that HIV/AIDS caregivers have carried heavy burdens but, also, have seen some great rewards. Their work is highly stressful with only the strong able to continue for any long period of time without burnout (General Report, 1993). Wilson and colleagues (1996) stated that the caregivers in African-American communities have a difficult time where any outside help has also to be "legitimized" by the church. In other words, the informal caregivers often rely on churches for any type of help they receive from people they pray with. This is also relevant in Congo where churches have taken on the government role by assisting people.

Another study (Raveis and Siegel, 1991) provided some insights into the HIV/AIDS family caregiver experience by revealing a significant need for interventions designed to support caregivers. The need for the creation of supportive networks for HIV/AIDS caregivers cannot be overstated, but further research is required to help clarify and expand on how social support might have an effect on HIV/AIDS family caregivers. With this knowledge, "...health-care providers will be better prepared to anticipate difficulties faced by caregivers, plan appropriate interventions to address these difficulties, prevent future problems, and plan care based on theory and research." (Stajduhar, 1997, p. 79). This knowledge would be very helpful especially in Africa where "...the extended family and clan assume the responsibility for all services for their members, whether social or economic" (Shawky, 1972, p. 33).

Until recently, little information has been published about the enormous burden on the informal caregiver that exists in sub-Saharan Africa due to the HIV/AIDS pandemic. Sarason et al (1983) has also recognized that medical and social support for family caregivers in sub-Saharan Africa, in terms of how it is provided, by whom and under what circumstances, has hardly been approached or touched in international literature. The following are, however, the results of some recent studies of the African context of caregiver burden.

In Africa, people live in closely organized groups and willingly accept communal obligations for mutual support. The sick, the aged and the children are all cared for by the extended family. Panos (1990) noted that in the contexts of AIDS care and prevention, the extended family network found in many developing countries is a national strength. However, "... as the AIDS burden grows it can also easily be over-exploited" (Seeley et

al., 1993, p. 53). According to the same study, "some doctors and social scientists in Africa argued that for many people, the extended family as a safety net could be no more than a myth."

Folayan et al. (2001) surveyed people caring for a family member living with HIV/AIDS, community leaders, and other stake holders (e.g., non-governmental organizations) to assess the role of non-governmental organizations in the control of HIV infection in Nigeria. They used the findings of this study to make recommendations on issues related to the health care of people living with HIV/AIDS. Twelve HIV seropositive persons, 13 community leaders and 34 AIDS orphans were interviewed. Using semi-structured interviews, the study underlined that the burden of care for AIDS patients often falls on the female family members. They concluded that the poor education of the family members, due to financial difficulties for paying school fees and related costs to schooling, limited their ability to provide appropriate care for family members with HIV/AIDS. However, Folayan et al. (2001) did not elaborate on how improved education would help family members provide better care to the family member with HIV/AIDS.

Traditionally, HIV/AIDS related research has focused on the biological and preventive aspects of the HIV epidemic, on the cure for patients with AIDS (PWAs) and on the support for asymptomatic HIV infected persons (positive living). Since most PWAs in Africa remain at home and receive either some care through home-based care programs or receive no formal health care services at all, the main burden for their care rests on family members, and especially upon the women.

Assessing caregiver burden and how it might adversely affect health status is especially relevant to the Democratic Republic of Congo as a high HIV prevalence country. Caregiver burden can be defined not only as the implications of caregiving on family relationships and crisis planning, but also in terms of its impact on personal health (physical, emotional and psychological), the amount of help needed and the financial costs of caregiving. Caregiver burden may also be understood as a composite of stress factors - potentially verifiable and observable effects such as personal activity limitations (Reinhard, 1994), and other subjective factors such as caregiver perception (Semlyen et al., 1998), as well as coping ability (Sander et al., 1997). Statistically valid and reliable

measures can be used to successfully identify and quantify burdens on relatives and caregivers (Kreutzer et al., 1994).

3.2. Stigma on patients and their families

In most societies, health and illness are at one level a private, individual matter, while at another they have implications for relationships and social functioning. HIV and AIDS are no exception to that rule. For each HIV/AIDS patient, there is also an affected family. The impact of HIV disease on an individual are inextricably linked to the social context where prevention, infection, illness, treatment and care occur (Bor and Elford, 1993). One of the social consequences of HIV/AIDS disease is the stigma and the discrimination for both the family and the HIV/AIDS patient. In fact, while the family can be an important source of emotional and practical support for the person infected with HIV/AIDS, the family may also experience similar problems to the HIV/AIDS affected person, including social stigma, isolation resulting from secrets, shame, guilt, loss and despondency (Turner and al., 1990).

Stigma can be defined as "a mark of disgrace, a stain or reproach on one's reputation" (Avis et al., 1963, p. 56). In other words, stigma is the discrediting of an individual or group in the eyes of others. Stigmatization is the process or evolution of devaluing rather than a simple act. "Discrimination occurs when a distinction is made against a person that results in his/her being treated unfairly and unjustly on the basis of his/her belonging, or being perceived to belong, to a particular group" (Aggleton, 2002, p. 4).

The psychological state of HIV/AIDS patients, and their perception of the stigma associated with the disease have both been studied extensively. According to Fredriksson and Kanabus (2000), from the moment scientists identified HIV and AIDS, social responses of fear, denial, stigma and discrimination have accompanied the epidemic. Discrimination has spread rapidly, fuelling anxiety and prejudice against the groups most affected, as well as those living with HIV or AIDS. It goes without saying that HIV and AIDS are as much about social phenomena as they are about biological and medical concerns.

In their research on "*AIDS and the urban family: its impact in Kampala, Uganda,*" McGrath et al. (1993) concluded that subjects did not tell their families about their HIV/AIDS infection because the family would worry, they feared rejection, it was none of their business, or they wouldn't understand. Family members expressed fear of loss, shock and disbelief at the diagnosis, but did not reject the subject or fear infection. Moreover, "persons with AIDS and their families expressed fear of rejection from those outside the household due to the perceived stigma associated with AIDS. The labelling of someone as having AIDS relates to their physical condition, so with declining health, subjects and their families usually avoid outside contacts" (McGrath et al., 1993, p. 55).

Aggleton (2000) points out that the forms of stigma and discrimination faced by people with HIV/AIDS are multiple and complex. Individuals tend to not only be stigmatized and discriminated against because of their HIV status, but also because of what this connotes. Recent UNAIDS-sponsored research in India and Uganda shows that women with HIV/AIDS may be doubly stigmatized both as women and as people living with HIV/AIDS when their seropositivity becomes known. Many factors contribute to this HIV/AIDS-related stigma: HIV/AIDS is a life-threatening disease, people are afraid of contracting HIV, the disease's association with behaviours, such as sex between men and injecting drug-use, that are already stigmatized in many societies. People living with HIV/AIDS are often thought of as being responsible for becoming infected. This is because religious or moral beliefs lead some people to believe that having HIV/AIDS is the result of moral fault (such as promiscuity or "deviant sex") that deserves to be punished (Fredriksson and Kanabus, 2000).

In some cultures, laws, rules and policies also constitute the "aggravating factors" of stigma and discrimination toward people living with HIV/AIDS and their families. Such legislation may include compulsory screening and testing, as well as limitations on international travel and migration. In most cases, discriminatory practises, such as the compulsory screening of "risk groups," both furthers the stigmatization and creates a false sense of security among individuals who are not considered at high-risk (Fredriksson and Kanabus, 2000).

The foregoing demonstrates why it is important to have knowledge of patterns of care in these stigmatized families and to assess whether additional support is required to help the family fulfil its caregiving role.

3.3. Conceptual framework

For the purpose of this study, we used the concept of health determinants; a process that acknowledges that health is affected by social, environmental, economic and personal factors. For example, social cohesion, which can be defined as the existence of mutual trust and respect between different sections of society, contributes to the way in which people and their health are valued. Consequently, "there is increasing evidence that communities with high levels of social cohesion have better health than those with low levels of social cohesion" (Stansfeld, 2000, p. 169).

The determinants of health addresses the entire range of health determinants, including, but going beyond, the risk factors for a specific condition or disease. It seeks to reduce barriers to health and increase opportunities for the population to reach better levels of health. Good health can improve people's overall well-being and quality of life. Conversely, people's well-being and quality of life can positively influence their health status.

Applying this concept to my study dictated that I consider the health status of the women caregivers as a function of multiple influences at the household level such as physical work, psychological stress, stigmatization by others, economic constraints (most financial resources go into the care of their AIDS patients), and social distress. All these aspects and others have been considered in the study in regard to the design of the questionnaire and focus groups discussion guidelines.

The determinants of health are factors and conditions which have an influence on the health of individuals and communities. Critical to this definition is that the determinants do not act in isolation from each other. Rather, it is the complex interaction of these determinants that has an impact on the health of individuals and communities (Health Canada, 1996).

The following determinants of health are recognized by Health Canada (1996) under its Population Health Framework:

- Income and Social Status: The healthiest populations are those in societies which are prosperous and have an equitable distribution of wealth,
- Education: Health status improves with each level of education. Education increases opportunities for income and job security, and gives people a sense of control over life circumstances,
- Employment and Working Conditions: Unemployment is associated with poorer health. People who have more control over their work circumstances and fewer stressful job demands are healthier and often live longer than those involved in more stressful or riskier work and activities,
- Social Environments: Social stability, safety, good working relationships and cohesive communities provide a supportive society that reduces or eliminates many potential risks to good health,
- Physical Environments: Physical factors in the natural environment, factors in the human-built environment such as housing, workplace safety, community and road design are also important influences,
- Personal Health Practices and Coping Skills: Social environments that enable and support healthy choices and lifestyles are key influences on health, as are people's knowledge, intentions, behaviours and coping skills for dealing with life in healthy ways,
- Biology and Genetic Endowment: The basic biology and organic makeup of the human body are a fundamental determinant of health. Genetic endowment provides an inherited predisposition to a wide range of individual responses that affect health status,
- Healthy Child Development: The effect of prenatal and early childhood experiences on subsequent health, well-being, coping skills and competence is very powerful,
- Health Services: Health services, particularly those designed to maintain and promote health, to prevent disease, and to restore health and function, contribute to the population's health,

- Gender: Gender is the basis for an array of society-determined roles, personality traits, attitudes, behaviours, values, relative power and influence that society ascribes to the two sexes on a different basis,
- Culture: Belonging to a particular race or ethnic or cultural group influences population health and
- Social Support Networks: Support from families, friends and communities is associated with better health. Effective responses to stress and the support of family and friends seem to act as a buffer against health problems.

Since social support is an important determinant of health, it is essential to look at social support in relation to those living with HIV/AIDS. Social support seems to be imperative in order to retain a certain level of hope for patients of HIV/AIDS who suffer from stigma and discrimination. Since options for formal support are strictly limited in Africa in general and in Congo particularly, social support constitutes an important buffer for family caregivers of HIV/AIDS infected people. Because of the critical role that social support plays as a buffer, the following review of the literature focuses on the relationship between social support and the health condition. The social support literature can be divided into three orientations.

In the first orientation, studies address the stress-buffering effect of social support (Gottlieb, 1983; Cohen and Wills, 1985; Kessler and McLeod, 1985) positing that social support is more effective for people under high stress than for those under low stress (Cohen and McKay, 1984), because people tend to be more helpful to others when their situation becomes critical. In the early stages of the disease, it seems that little care is given. In fact, there seems to be a form of negligence at play. This is true for people with AIDS and their caregivers, because when in the early stages of HIV/AIDS, people can't see what is happening so they don't offer support. But as the severity of the situation becomes apparent, others become more willing to provide support.

The second orientation constitutes those studies that suggest social support can be negatively related to distress (Hobfoll, 1985). In other words, social support cannot be assumed to always benefit the recipient. In particular, under chronic or severe stress, social support may prove a disappointment as it is hard to mobilize or because it simply

cannot meet the extreme demands (Hobfoll, 1985; Hobfoll and London, 1986). Families may simply lack competency in dealing with HIV issues. In other words, they do not know how to effectively cope with the myriad of concerns, issues and feelings aroused by the crisis. It may be that the family desires to be supportive, but instead becomes immobilized by the information, and so becomes an inefficient and, at times, negative source of support. In Congo where resources are already limited, social support can be a source of frustration. When resources are often not sufficient for normal day-to-day living, it is impossible to provide the increased supports that are required.

The last orientation contains studies that posit a direct relationship between social support and distress, suggesting that social support contributes to general well-being regardless of stress level (Bloom, 1982; Frankel and Turner, 1983; Bruhn and Philips, 1984). Some previous research has also found strong relationships between social support and positive outcomes for health and well-being throughout the life-cycle. In an early review, Cobb did report the following conclusion: "adequate social support protected people in crisis from a variety of pathological states; from birth to death, as a result of chronic diseases, depression and other illnesses" (Cobb, 1976, p. 304). While, there is support for the view that social support and positive outcomes for health are related, Cohen and Syme (1985) state that the relationship is almost entirely correlational. It is not known why social support is associated with health, but two hypotheses have been proposed to explain the relationship: the main or direct-effect model and the buffering model.

"The direct effect model posits that social support enhances health and well-being irrespective of stress because large social networks provide people with regular positive experiences and a set of stable, socially rewarded roles in the community" (Cohen and Wills, 1985, p. 19). The authors explain that the perception that others will provide aid in the event of a stressful situation has an overall positive effect on people's health and may elevate their self-esteem, stability and control over their environment. The impact on people's psychological states may also affect the health outcome by influencing the susceptibility to illness by its impact on the immune system or through the influence on behaviour and physiological responses.

In the buffering model, resources provided by others have beneficial outcomes by protecting people from the pathogenic effects of stress (Cohen and Syme, 1985). Intervention by supports may redefine and reduce the potential harm posed by the occurrence and/or they may aid by confidence building so the event is not recognized as stressful. Cohen and Syme (1985, p. 21) suggested therefore "...a second way the buffer model works is by the support directly intervening between the source of the stress thereby reducing or eliminating the pathological outcome or by influencing the responsible illness behaviours or physiological processes." The third and last orientation particularly is most relevant to our study because we are assuming that in the context of poverty in Kinshasa, the more caregivers are helped, the more their tasks are facilitated and the more their husbands benefit.

In other research, Noh et al. (1990) studied the presence or the perception of social support on the psychological distress and physical well-being of the HIV/AIDS patients. They have concluded that men who had close confidants experienced less emotional strain imposed by the threat of exposure to HIV. Those outcomes are similar to many others studies which have found that HIV positive gay men who reported having social supports have been reported to experience less emotional distress (Blainey et al., 1991), demonstrated active-behavioural coping (Wolf et al., 1991), and lower levels of mood disturbance, greater global health perception and higher self-esteem (Wolcott et al., 1986).

Chapter 4: Study Design

The current chapter presents the methodology of the research project. A brief review of the purpose of the study is followed by the research questions and the hypothesis. Then a general overview of the methodology will be given along with a description of the context of the study and the participants. After that, the details of the methods employed and the limitations of the results will be explained. The section on the ethical considerations will end this chapter.

4.1. Purpose, research questions and hypothesis

The purpose of this research was to assess the caregiving burden of women caring for spouses with HIV/AIDS in the Democratic Republic of Congo. The following constitute the research questions:

1) What are the problems faced by women as informal caregivers for spouses living with HIV/AIDS?
2) Among those problems, which ones influence the women health status and how?
3) How do women deal with those health issues?
4) What support mechanisms would mitigate the impact of HIV/AIDS on these caregivers?

Answering those questions addresses another purpose of the study, which is to provide information that will enhance program planning for support of caregivers.

The study assumes that women already have a heavy burden of responsibilities for the health and welfare of their families, which includes working for wages, ensuring adequate food and housing for the family, child care and child education, etc. When they must care for a spouse with AIDS, an extra burden is added. There is very little assistance and support available to these women in Democratic Republic of Congo. Therefore, it is hypothesized that:

1) Women as informal caregivers for spouses with HIV/AIDS face many problems in terms of social discrimination, finance, stress, food, medication supply, etc.

2) Those problems have a negative impact on the women's health.

4.2. General overview of methodology

This study includes quantitative and qualitative research methods in order to capture the broad context and the conditions under which the care of HIV/AIDS patients in the home occurs. The quantitative research method consisted of administering a questionnaire containing forty questions on the general state of health of women and on the health condition of the HIV/AIDS patients, as well as on the context in which the care was given. Ethnography, which is a method used to describe a cultural group or to describe a phenomenon associated with a cultural group, was the primary qualitative component of this study.

4.3. Context and Participants

In Kinshasa, each zone or sector has several public and private health institutions, which include home-based care centres. These centres usually operate as independent agencies where people can receive services for different kinds of health problems. With regard to the home-based care program, every home-based care centre has in-patient beds as well as an outreach program for the care of sick patients in their homes. As HIV/AIDS is the major health issue in Kinshasa, many of the patients have medical conditions related to HIV/AIDS.

The home-based care program staff visit each client at home for an average of two times per month for three hours each time, and their care involves basic medical care, counselling and providing food and health education. There is close collaboration between home-based care program staff and family members of the patients. Family members receive instructions for the care of the sick patients, which they follow until the next visit. In the case of an emergency, family members may bring the patient to the home-based care program centre or get the staff program members to come to their home before the next scheduled visit.

Each home-based care centre has 20-25 nurses, who are supervised by the home-based care manager. In addition, three to five medical doctors work in the centre to provide outpatient services. The home-based care program in Kinshasa is a publicly

funded government service. Home-based care is part of the Primary Health Care program in Congo.

In contrast with hospitals and (public or private) clinics where people go only for treatment and where care is expensive, home-based care receives people for both prevention and treatment. User fees are in place and charges start at five Canadian dollars for one clinical visit. The user fees are part of the budget of the centre and help to buy drugs, stationery, and provide transportation for outreach nurses, etc. The home-based care centre provides treatment and prevention services close to the people and therefore, makes these services accessible and affordable to the poorer segments of the population.

The zone of Bumbu in Kinshasa was chosen as the area for the study for a number of reasons. First, Bumbu is an especially poor area of the city with a population of 192,318 (Kinshasa Town Administrative Hotel, 2002). Secondly, in Bumbu almost 80% of the population are uneducated and 75% are unemployed. Most of people make a living from trade activities. Prostitution is a major issue in Bumbu, and 25% of sexually active people are HIV seropositive status. Despite the presence of a Maternal and Infant Health Centre, a home-based care program and many other clinics, the number of HIV/AIDS infected people is still increasing in the zone.

The non-governmental agency we worked with, as part of this study is Sacome+ the details of which were given in the second chapter. However, in addition to the two visits a month that all the home-based care programs provide, Sacome+ also provides food (Soya, manioc, oil, corn, etc.) twice a month and medications to people infected with opportunist diseases. Sacome+ also provides rooms to the patients and their families who have nowhere to live. Clients go to the Sacome+ centre, as they want. There is also a program for dying patients and their families at Sacome+. This program consists of preparing funeral ceremonies and helping the patients and their families to deal with impending death.

The study was conducted in cooperation with the Demography Department of the Economic Sciences Faculty of the University of Kinshasa where the researcher had been both a student and a Research Associate. The Demography Department of the University of Kinshasa is already involved in HIV/AIDS related research in the zone of Bumbu. A research team was made up of four members: Professor Bernard Lututala Mumpasi, the

director of Sacome+, the Sacome+ coordinator of the Persons living with HIV/AIDS' program and the researcher.

Professor Lututala is the Economic Sciences Faculty Vice-Dean of Research and former Head of the Demography Department. He previously agreed to support the study by being the fieldwork supervisor. He made necessary arrangements for municipal approval of the project prior to beginning the project (Appendix A). The cooperation between Prof. Lututala and the researcher has been very helpful in carrying out the fieldwork as planned. The author's previous work on "Ethnic origin of women and procreator behaviour in Kinshasa" (Matukala, 1996) also facilitated the execution of this study.

The role of the Sacome+ director was essentially to provide logistical support. He provided a room, some chairs and tables to work with. He also assured the Sacome+ staff and members that the study was legitimate and encouraged their cooperation. The Sacome+ coordinator of the Persons living with HIV/AIDS' program, who is himself infected with HIV, and has two wives and one child who are also infected with HIV, took part in the study as both a research assistant and a resource person. The women in the program regard the coordinator as their partner, so they were comfortable with his roles as a research assistant for the study. The coordinator is well-educated (with a university degree) and former military commander, and assisted in dealing with the financial compensation for participants in the study.

Participants of the study were identified from the urban population of Bumbu through the Sacome+'s existing client list. Eighty women who were caregivers for husbands who had been living with HIV/AIDS for at least six months and who voluntarily agreed to participate in the study were recruited. Men and women who were not providing care to their spouses, women whose husbands were suffering from diseases other than HIV, and men were automatically eliminated from participation in the study. Because the women came from all over the city, speak the same language and live generally in the same conditions, this number is large enough to provide the essential information the study was seeking.

We wanted to focus on caregivers whose family responsibilities included caring for children so eligibility included being between 18 and 49 (Table 3). At 18 women

reached the age of majority and may have begun childbearing. After 49, women usually reached menopause and are past childbearing years. If they do have children, the children are more likely to be older and able to care for themselves. Therefore, women between 18 and 49 are more likely to have children in the home. As for the general population of Kinshasa/Congo, the structure of our sample is young. 52.6% of the participants are not yet 33 years of age.

Table 3: Distribution by age of the study participants

Ages in years	Frequency	Percent
18-22	4	5.0
23-27	11	13.8
28-32	27	33.8
33-38	20	25.0
39-43	11	13.8
44-49	7	8.8
Total	80	100.0

All women who volunteered to participate in the study were recruited into the study as they were identified. Confidentiality was assured by conducting the interviews with the caregivers in the Sacome+ centre, which was the participants' preference. Sacome+ staff were not involved in the recruitment process, in order to ensure that the women didn't feel any coercion to participate in the study, and to ensure that their care would not be compromised in any way.

Key-informants and staff members of the Sacome+ were also participants in the study and took part in the Focus Group Discussions (FGDs). Their participation was on a volunteer basis.

4.4. Quantitative methodology

In this section, the sampling strategy and the interviewing process are discussed, followed by an explanation of how the reliability and validity of the questionnaire were established.

4.4.1. Sampling strategy and the interview process

The health status of the participating women was measured using a questionnaire (Appendix B) that was developed, validated and used in Canada (Canada Population and Health Survey, and Health Promotion Survey). This questionnaire was modified to address the local conditions of the Democratic Republic of Congo and the needs of the study. It comprises a maximum of forty questions not only on the general state of health of women, but also on women's health in Kinshasa and the context in which the caregiving of the HIV/AIDS infected persons was occurring.

Previously written in English, the questionnaire was translated into French on paper by the primary researcher. In the field, the primary researcher read from the French verbally into the local language Lingala. Responses were recorded in French. The researcher, who is fluent in Lingala, French and English, translated the responses into English after the interviews were completed. The fieldwork supervisor of the study, Professor Lututala Mumpasi who is bilingual, verified that translations were accurate. Eighty women recruited to the study completed this interviewer-administered questionnaire.

The data for this survey were collected in Bumbu, Kinshasa from September to November 2002. The collection of data was based on a sample that was determined in two steps. The first step consisted of randomly selecting participants from the existing lists provided by the director of Sacome+. A sample of eighty participants was drawn from a list of Sacome+ clients using simple random sampling. This sample of eighty participants enabled us to measure a rare condition or characteristic of 10% within a 95% confidence interval of 4.5% – 15.5%, which was considered sufficient for this study.

In the second step, the selected participants were visited in their homes by the research assistant and asked if they would like to participate in the study. The details of the study were given to them in an information letter (Appendix C). Those who agreed to

take part in the study were formally recruited into the study by the research team and asked to sign the consent form (Appendix D). The researcher carried out all the interviews because all the caregivers preferred to be interviewed by him rather than by the research assistant. For them, this was the only way to ensure confidentiality since the researcher was returning to Canada after the study was completed. The women also chose to conduct the interviews in the Sacome+ centre. This avoided the curiosity of the neighbours that would be occasioned if the interviews had to be conducted at their homes.

Prior to each interview, an appointment was set up between the research assistant and the women. The women were interviewed one by one. Participants' cooperation was good and sensitive information was provided. The ambiance was cordial and everything was done with a mutual respect between the women and the researcher, because the women truly hope that the study will contribute to improve their situation.

4.4.2. Reliability and Validity of quantitative data

The researcher developed the questionnaire using items from the "Canada Health Promotion Survey" (1996) and "Canada Population Health Survey" (1998) that were relevant to the focus of the research. These questionnaires have been shown to be reliable and valid (Statistics Canada, 1996 and 1998). Wording needed to be adapted to Congolese local conditions. For example, in Canada doctors provide primary medical care, but in Congo it is nurses who most often provide this care, thus "nurse" would replace "doctor" in a question.

The researcher's supervisory committee reviewed the revised version of the questionnaire before the researcher went to Kinshasa, Congo. Previous questionnaires from many other surveys carried out in Congo by the Demography Department of the University of Kinshasa also provided direction for the wording of the final version of our questionnaire. Another method that was used to increase the reliability of the questionnaire was clearly formulating terms for health problems (and their indicators) and where necessary explanations for each question were provided. This was done to ensure that all the caregivers had the same understanding of the questions. We also

improved the reliability of the questionnaire through numerous drafts and preliminary versions, as well as pre-testing the questionnaire.

In order to assess possible interviewer bias, the primary researcher conducted random-repeat interviews: Five randomly selected women from the list of the eighty women were asked to be interviewed twice (five days apart), once by the researcher and once by the research assistant. This was done in order to determine the degree of influence that the interviewer's personal background and the relationship between the interviewer and the interviewee might have on the interviewee's responses. All the data collected by the researcher and the research assistant were congruent. In this manner, we were able to check that both "the conclusions of the research...[were]...supported by the data" and "the reader of the report is able to transfer the research findings to contexts outside of the study situation to other settings" (Mayan, 2001, p. 26).

The last effort to ensure validity of the responses was to use the triangulation technique, which is a combination of research methods in the study, to verify the findings. Validation was sought through comparison of the semi-structured interviews, the focus group discussions and the surveys regarding self-reported health status.

4.5. Qualitative methodology

Three features characterize qualitative research and distinguish it from quantitative research: the *emic perspective* (or eliciting meaning, experience, or perception from the participant's point of view, rather than from the researcher's perspective), the *holistic perspective* (or an approach to the phenomena of interest by considering and including the underlying values and the context as a part of the phenomena) and the *inductive and interactive process of inquiry* (this must be between the researcher and the participants, with the researcher driving the analytic process as s/he gains comprehension and insight about the phenomena of interest (Morse, 1992).

According to Morse (2002), there are three principal qualitative methods: phenomenology, grounded theory and ethnography orientation. The qualitative arm of this study used the ethnographic approach.

4.5.1. Benefits of an ethnographical approach

Ethnography seemed to be appropriate here because it is a method based on the assumptions that culture is learned and shared among members of a group and, as such, may be described and understood (Morse, 1992). The central elements to ethnography are: the researcher uses description and a high level of detail, he or she explores cultural themes of roles and behaviour of the group, the overall format is descriptive, analytical and interpretative and the research is concluded with a question. Briefly, ethnography's primary goal is to understand the full range of cultural roles, norms and values of a particular group.

The ethnographic approach was very useful because it allowed us to examine the circumstances under which women take responsibility to care for family members who are living with HIV/AIDS, how this responsibility affects their health and how they cope with the health issues when they are affected.

4.5.2. Techniques of Ethnography approach

We used three ethnography research techniques for this study: field notes, focus group discussions and semi-structured interviews.

4.5.2.1. Field notes

Field notes technique consists of describing as literally and accurately as possible what is being observed from the participants in their setting for a long period, almost three months in our case. Because the research assistant, Professor Lututala and the researcher are from Congo and speak the same language as all the participants, cultural immersion was not necessary. We easily were able to internalize the basic beliefs, fears, hope and expectations of the women who deal with this situation, but we also ensured that we did not make assumptions based on our cultural background. So the observation took place at the participants' home, at the home care program centre and, sometimes, on the street. The type of information obtained from the observations included relevant physical, emotional/psychological state (e.g. nature of the relationship between patients and caregivers (good, bad, superficial, deep), reactions to patients needs, etc.). The researcher recorded observations and field notes in a copybook.

4.5.2.2. Focus Groups

Three focus groups discussions (FGDs) were organized and conducted for comparison of responses between groups of interest. The topics of the focus groups were designed to address the issues identified through caregivers' responses to the questionnaire and the semi-structured interviews. A pre-determined question guide (Appendix E) was developed and used. The three FGDs are summarized as follows (Table 4):

Table 4: Characteristics of the FGD participants

Population	Total Number	Number of Females	Number of Males	Language of discussion
1) Sacome+ staff	6	3	3	French
2) Informal caregivers	12	12	0	Lingala
3) Key informants	5	3	2	French

1. One FGD with six staff members of Sacome+ (three men and three women). This FGD helped us to know what Sacome+ staff members think about women's problems as caregivers for HIV/AIDS infected husbands and about the Sacome+ activities, leading to a gender relevant approach. The Sacome+ staff members who took part in the study were contacted directly by the research team and myself during their work with the women and formally recruited into the study as previously described.

2. One FGD with twelve caregivers who were recruited from the participants who completed the questionnaire. From this group, we gathered information about the problems faced by women as caregivers and whether they are different from those they faced before becoming caregivers. This allowed us to determine how caregiving impacts women and how women attribute their different health problems to caregiving. The FGD with caregivers also provided a better understanding of the caregiving experience.

3. One FGD with five key informants (health planners, policy makers, civic leaders, etc.) from the zone of Bumbu. The key informants provided us with information on their experience with the home care of AIDS patients, the appropriateness of the home-based care program for affected families and the need for expanding and strengthening existing services to the community.

4.5.2.3. Semi-structured interviews

The content of the semi-structured interviews related to information on caregiver burdens as a result of the self-reported health status questionnaire. The guidelines for the semi-structured interviews (Appendix F) were developed in the field based on information obtained from the questionnaire survey, field observations and Sacome+ staff observations. The interviews were used to elucidate information on the problems that women as caregivers are facing on a day-to-day basis. In addition, the semi-structured interviews incorporated a series of questions based on the findings from the health status questionnaires.

A sub-sample of twelve women, from the larger sample of 80 women who participated in the quantitative survey, participated in the semi-structured interviews to discuss their problems as caregivers.

4.5.3. Validity of the qualitative data

As with the quantitative inquiry, the essence of the qualitative data is that the conclusions of the study come only from the data. This means that the social context and the reality of the situation are being described as observed.

To ensure validity of our qualitative data, each research interview guide was reviewed to determine the final version. With the help of research assistant and Professor Lututala, we reviewed the interview guide with a small number of home care clients to test for understanding, language, and sensitivity of questions. The results were used to establish the appropriate wording and understanding. The instruments were checked for linguistic reliability by translating the English FGD topic list into French and then having Professor Lututala translate the questionnaire back into English. The tests and pilot focus group discussion also helped us to prevent some negative reactions from the participants and to ensure clarity of the guiding questions.

Based on the foregoing, one can assume that the four principles of rigour (credibility, transferability, dependability and conformability) underlined by Marshall and Rossman (1995) for qualitative data have been reached in this study. The principle of credibility is reached when it is clear that the subject in question, which in this study is the caregiving experience, has been accurately understood and characterized (Marshall

and Rossman, 1995) and the transcripts from the interviews and FGDs have been useful. In the same way, our findings are transferable to another population with similar, but not necessarily the same traits as the population of our study and other researchers may easily reach the same conclusions from our data. Even if a qualitative study may not always sustain generalization and exact replication is difficult, which is its main weakness, the conclusions drawn from this study are valid.

4.6. Data analysis and interpretation

Data analysis and interpretation of our findings are the subject of the following chapter. The analysis of the quantitative data is primarily descriptive with some inferential analyses. SPSS was used to compute some measures of central tendency and of dispersion in order to describe the characteristics of the women and the importance of their health problems.

Qualitative analytical techniques included content analysis (theming, coding, categorizing, abstracting). Abstracting was done by transforming data from individual instances by creating, exploring and using general categories that are derived from the data.

Steps in content analysis:

1) Identify the data set to be used: field-notes, transcripts, videotape recordings, etc. All the records have been translated into English.

2) Code the messages into the categories.

3) Analyze the data and interpret the results.

4.7. Ethical considerations

The ethical concerns for this study were how consent from the participants would be obtained and the confidentiality of their responses. These potential ethical concerns were addressed in a number of different ways.

An information letter (Appendix C) and a consent form (Appendix D) were read and explained to every participant. After participants were given the rationale for the study and its implications, participants were asked to sign the consent form. Those participants, who could not write, used their fingerprint, which is common practice in

Congo since almost 80 percent of the population are illiterate. The information letter and the consent form state clearly that the participants have volunteered to release information in the focus groups about their life conditions in general and especially their health as caregivers of HIV/AIDS patient family member. In addition, participants were given a detailed explanation that they could leave the study at any time and that their care by the Sacome+ staff and members would not be compromised if they left the study before completion.

Participants were assured that all their comments would remain confidential. Any identifying information that was given in the focus groups, semi-structured interviews and in the questionnaire was shared only between people of the research team. No names were recorded on the data collection sheet. The confidentiality was guaranteed by conducting the interviews myself at the Sacome+ centre as the participants requested. When conducting the focus group discussions, certain rules were followed. For example, because we could not guarantee confidentiality, participants were asked not to talk about what occurred in the focus group after the fact.

The presence of a HIV/AIDS infected person in the research team as a research assistant assured that participants talked openly and freely about their experiences. At the same time, having a research assistant who has a university degree as well as experience in this type of study (he conducts all the HIV/AIDS studies for Sacome+) helped us to approach sensitive topics in the appropriate way. Using these protocols, the private and sensitive nature of the information requested did not pose any problem.

In order to ensure that participating in the study would not incur personal financial costs to the participants, transportation allowances were paid. Each participant received the equivalent of C$5 to cover expenses for transportation and the provision of lunch. In this way, participants did not have to use their own money to participate in the study.

The Ethical Review Board (B: Health Research) of the University of Alberta gave ethical approval for this research. The study was also approved by the following local agencies: the Congolese Minister of Social Affair and Public Health, the department of demography of the University of Kinshasa and the Sacome+ General Directorate.

Chapter 5: Quantitative Findings

In this chapter, the quantitative findings of the interviews with eighty informal caregivers are presented. The study found that caregivers were faced with multiple problems coping with the effects of HIV/AIDS: They are unemployed and they live in poverty; they were not prepared to be caring for their HIV/AIDS infected husbands; and they don't receive enough help in their caregiving role. An additional concern was for their own future and their children's future because all of the caregivers in the study are also infected with HIV/AIDS.

The details of the findings are presented in four sections. The first section describes the socio-economic, cultural and demographic characteristics of the informal caregivers. The second section discusses their roles and main difficulties that arise in their task as informal caregivers. The third section focuses on the self-reported health conditions of the caregivers both for the last twelve months and since they have been informal caregivers for the HIV/AIDS affected husband. The fourth section addresses the caregivers' challenges they face with respect to their own and their husband's health issues.

5.1. Socio-economic, cultural and demographic characteristics

The five main ethnic groups present in Kinshasa are represented: Kongo women (47.5%) are slightly over represented while the Mongo women (8.8%) are slightly under represented. Luba and Kwilukwango women represented 2.5% and 11.3% of the sample respectively. The remaining 20% of the sample included a combination of women from the Ubangi, Swahili and other ethnic groups (Table 5). This distribution of the sample by ethnic groups is very similar to the distribution of ethnic groups in the Kinshasa population from which Kongo, Luba and Kwilukwango people represent more than 70% (Statistics National Institute, 2002).

All the participants believe in God, but they belong to several different religious groups (Table 5). The data have shown that Catholics are 31% and Protestants are 30% of the sample. The next religious group represented was the Kimbanguists, who made up 8% of the sample. "The Kimbanguist Church, which is a member of the World Council of Churches, was founded around 1925 in Democratic Republic of Congo by Simon

Kimbangu" (Tambashe and Shapiro, 1991, p. 20). Only 1% of the participants in the study practiced Islam as a religion. The remaining 30% of the sample represented the numerous other religious groups in Kinshasa such as "Nice God", "Sacred spirit", Salvation Army, etc. (Table 5). As with the ethnic groups, the distribution of the participants by religion is representative of the national situation, as more than 60% of the Congolese are either Catholic or Protestant. Respondents were not specifically asked about traditional spiritual beliefs.

Of the 80 informal caregivers who participated in the study, 23.8 % and 7.5% of the participants had some elementary or completed elementary education respectively. Approximately half of them (48.8 %) had some secondary education (Table 5). Two and one-half percent of the participants never attended school, 15.0% completed secondary education and 2.5% had completed some college, technical or nurse's training. In comparing the study sample with the Kinshasa population, the level of schooling of the sample appears to be distinctly higher than that in the population where 80% are not educated and only 5% (men and women included) have a university degree (National Institute of Statistics, 2002). This can be partially explained by the fact that all the participants were urban and married and Congolese men often choose their wives among women with a certain level of education.

Women who provide informal caregiving usually disrupt their economic and social activity, so almost all of them (98.7%) didn't work and didn't have any formal income generating activity. Consequently, the majority of them (97.5%) earned income less than US $1,000 before taxes in 2001. Only 2.5% of them had the income between US $1,000 and $5,000. To be considered as employed (self-employed or employed by someone else), a woman was required to have pursued an activity for pay or profit for a minimum of three months. They also stopped taking part in social activities and reduced their contacts outside of the household. Participants who reported some outside contacts (98.7%) found that helpful because it was easier to avoid any obligation to divulge or talk about their husband's seropositive HIV status.

Many of the women mentioned that they didn't own their own house. Only 31.2% were renting their house and 68.8% couldn't even afford to do so. Those who were not renting a house stayed either with their family, or with their husband's family or with a

friend, the Community house, the Military Camp (those whose husbands have a military job), the Home Care Program centre and the church.

Table 5: Participants' socio-economic and cultural characteristics

Variables	n = 80	%
Ethnic Group		
- Kongo	38	47.5
- Luba	10	12.5
- Kwilu-kwango	9	11.3
- Mongo	7	8.8
- Ubangi, Swahili and other	16	20.0
Religion		
- Catholics	25	31.2
- Protestants	24	30.0
- Kimbanguists	6	7.5
- Islam	1	1.2
- Other religion	24	30.0
Level of Education		
- No schooling	2	2.5
- Some Elementary	19	23.8
- Completed Elementary	6	7.5
- Some secondary	39	48.8
- Completed Secondary	12	15.0
- Some college, technical or nurse's training	2	2.5
Employment Status		
- Full-time Employed	1	1.3
- Not Employed	79	98.7
Total household income before taxes		
- Less than US $1,000	78	97.5
- Between US $1,000 and 5,000	2	2.5
Limited social activities		
- Yes	79	98.8
- No	1	1.2
Home		
- Rent	25	31.2
- Other	55	68.8

With respect to utilities, Table 6 indicates that 59% have both water and electricity where they live and 11% don't have either water or electricity (this proportion probably belongs to the group of women who are renting). As also shown in Table 6, only 15% of the sample owned both a TV and a radio, 77.5% didn't have both, but 7.5% had a radio only.

Table 6: Participants' materials and utilities

Variables	n = 80	%
Having Water and/or Electricity		
- Neither Water nor Electricity	9	11.2
- Electricity but no Water	5	6.2
- Water but no Electricity	19	23.8
- Both Water and Electricity	47	58.8
Owning Radio and/or TV		
- Neither Radio nor TV	62	77.5
- Radio but no TV	6	7.5
- TV but no Radio	0	0.0
- Both Radio and TV	12	15.0

All the informal caregivers participating in the study were married. Thirty-five percent of them reported that they were in a monogamous relationship. The others were in polygamous relationships. Polygamy is a highly valued tradition in Congo, so it is common to find men with many wives at the same time.

The participants ranged in age from 18 to 49 years (see chapter 4). All of the participants had children. The average number of children for each woman was 4.6, with more girls (almost 3 girls for each participant compared with 2 boys). This is somewhat lower than the Congolese national average (6.1 children for each woman). Several of those children are also HIV/AIDS infected at birth. A very small number of children, who were born without the HIV infection, were infected by a blood transfusion from their fathers, which they received for treatment of a medical problem. (In Congo blood transfusion is a common practice even for young children.) At that time, the fathers did not know they had a positive HIV/AIDS status.

Any participant used family planning. The main reasons for this were because they couldn't afford it and/or because they were aware of their husband's HIV/AIDS illness, and no longer have sexual relationships with him.

5.2. Role of informal caregivers and their principle difficulties

The informal caregiver plays an important role in caring for her husband infected with HIV/AIDS. This role cannot be replaced in the context of Kinshasa where the

government is not able to provide many services to its citizens. This study wanted to elucidate what those caregivers actually do for their husbands and how they do it. Does it require specific skills and responsibilities, and what does it mean to the women to be an informal caregiver? The study also assessed how much stress this caregiving role places on the women, and what social, emotional and even spiritual services are available to the women to help them cope with this caregiving stress.

As it was previously stated, an informal caregiver is defined as the woman who has the primary responsibility for looking after her HIV/AIDS infected husband at home, in the hospital or anywhere else. The primary responsibilities in this role include buying food, cooking, feeding the husband and seeking services or resources to help him. The caregiving tasks also include helping the husband bathe, use the toilet, dress, comb his hair or brush his teeth. Caregivers also help their husbands get out of bed or a chair, walk, and take medications. They must also monitor their husband's health, communicate with professionals and health care providers, arrange for someone to stay with him when necessary and help him deal with his emotions.

Finally, caregiving tasks consist of contacting the husband's employer (to ask for help and/or to keep the employer posted on the husband's situation), reporting the husband's state of health to his family and acting on the husband's behalf. This shows clearly that caregiving for the husband is an enormous responsibility for only one person. To get an understanding of how much work their caregiving entailed, participants were asked if they do all these tasks on their own or if they get support from anyone. If they did receive support, they were asked to elaborate on the nature of the support.

Although social support has been shown to be associated with better outcomes for both family caregivers and patients, only 25% (Table 7) of the participants said that they received any social support (help from their church, friends, family, family-in-law and husband's employer). Table 7 shows the relationship between receiving support and the level of stress that caregivers say they experience.

Table 7: Support to the caregivers and their stress level

Variables	Support to the caregivers					
	Yes (n = 20)	%	No (n = 60)	%	Total N = 80	%
Would you describe your life as:						
- Very Stressful	15	75.0	56	93.3	71	88.8
- Fairly Stressful	3	15.0	2	3.3	5	6.2
- Not Very Stressful	2	10.0	1	1.7	3	3.8
- Not stressful	0	0.0	1	1.7	1	1.2

Those participants who received support mentioned receiving diverse kinds of support: counselling, food, medications, assistance for children, etc. The majority (75%) of the participants said they did not receive any support and felt there was nothing to ease their burden as informal caregivers. On the contrary, they felt that because of the stigma associated with HIV/AIDS, they faced many of the following difficulties every day:

- Lack of money and medications: Most participants (98%) stated having financial problems, so they could not afford the cost of medications.

- Food problems (quantity and quality): The majority (98%) of the participants live in poverty and don't have access to nutritious food. Furthermore, HIV/AIDS and malnutrition often operate in tandem: poor nutrition increases the risk and progression of disease, and in turn, the disease exacerbates malnutrition.

On the other hand, HIV/AIDS can be both a cause and a consequence of food insecurity because it can lead to reduced food production, reduced income, increased medical expenses, thus causing reduced capacity to respond to the crisis. Inversely, food insecurity may lead to increased high-risk behaviours, for instance, labour migration or engaging in transactional or casual sex that increases the likelihood of infection. From this point of view, food and nutrition play an important role in prevention, care and mitigation activities in HIV/AIDS-impacted communities. The nutrition crisis of the participants represents an important issue.

- Stigma and ostracism: In the previous chapter, it was mentioned that social responses of fear, denial, stigma and discrimination against people living with HIV/AIDS and their families began almost as soon as scientists identified the syndrome. The participants were also invited to talk about whether they felt they were victims of stigma and/or ostracism. To this question, negative community (family, friends, neighbours, employers, etc.) reactions to women with a husband HIV/AIDS infected were reported by

90% of the participants. Only 10% of them said they did not consider themselves victims of stigma or ostracism, but this was because they did not disclose the HIV diagnosis of their husband.

Some of them told only their pastor or a few church members. A very few (3.8 %) had gone public in their churches. They did so for two reasons: they knew that by telling the church members, their story would remain confidential and they would receive the support that acknowledged their struggles as caregivers for their HIV/AIDS infected husband as well as relieve some of their husband's suffering. Otherwise, stigma and ostracism would undermine social support and would limit health-seeking behaviour, and reduce prevention and safe sex practice. Caregivers most often identified friends and neighbours (83.7%) as stigmatizing or ostracizing.

- Psychological problems: Participants reported that being aware that their husband will die leads to a psychological distress that poses significant difficulty in their caregiving role.

- Washing the husband, handling, holding and moving him without any help at all, managing the despair of the husband (who keeps saying he's tired of being sick, he would like to die and who sometimes refuses helps).

- Dealing with the husband's capricious nature and his quick tempered and shamed feeling. This is particularly true for the majority of the participants (76.5%) who still live with their husband. Husbands of 23.5% of the participants are hospitalized.

Ninety-five percent of the caregivers declared having a very hard time caring for their husbands. They described facing many difficulties that increased as the health condition of their husbands deteriorated. The study distinguished three levels of health of the participants' husbands: stays in bed most of the time (60%), lays and sits up in bed (36.3%); and up and about most of the time (3.8%). Those participants whose husbands belonged to the first two groups had a heavy caregiving load, since they have to do everything for their husbands. They also have increased exposure to the HIV/AID's virus because "within the family, caregivers, who have a greater degree of involvement in the caregiving process, are subject to more adverse outcomes" (D'cruz, 2002, p. 419).

This situation impacts on the informal caregivers mental health: 89% of them found their life very stressful compared to only 1% who didn't find it stressful; 6% and 4% find it fairly stressful and not very stressful respectively (Table 7).

5.3. Health condition of the participants

The participants were asked three specific questions about their health condition. The first question asked about their current and general health condition. The second question asked about their state of health in the last twelve months, and the third question asked about their state of health since they became informal caregivers. As expected, a large majority of participants (90%) reported that their current health condition was poor, and 10% of them considered their health status as fair. With regard to the health condition over the last twelve months, two sub-questions were formulated: the first asked whether the health condition required the caregiver to consult a professional health care provider. The second sub-question asked about health conditions for which the participants did not see a professional health care provider.

More than half (53.8%) of the participants declared that they did not consult any medical professional provider for their health conditions because they could not afford it. Most of the participants also reported low levels of overall happiness. In fact, 87.5% of them said that they were either unhappy with little interest in life or so unhappy that life is not worthwhile. Participants also added that they felt they would never be happy again and that they had suffered from many illnesses in the last twelve months.

Almost all of the caregivers (93.8%) reported that they had health problems since taking on the role of informal caregiver for their husband infected with HIV/AIDS. The main symptoms or diseases experienced by the caregivers are provided in Table 8. Of the symptoms and/or diseases experienced by the participants, headaches and gastritis come first with 45% and 29% respectively (Table 8). Vomiting comes immediately after with 15%, followed by fever, anorexia and stiffness with 10% each. Tuberculosis affected 7.5% of the participants. Anxiety constituted a symptom/disease for 5% of the caregivers while 3.8% have experienced depression. 3.8% of the participants also experienced diarrhoea and weight loss.

Table 8: Symptoms/diseases experienced by the participants

Symptoms and/or diseases	n = 80	%
- Headaches	36	45.0
- Gastritis/Stoma aches	23	28.8
- Vomiting	15	18.8
- Fever	8	10.0
- Anorexia	8	10.0
- Stiffness	8	10.0
- Cough	7	8.8
- Weakness	7	8.8
- Backaches	6	7.5
- Tuberculosis	6	7.5
- Low blood pressure	5	6.2
- Cold	5	6.2
- Typhoid	5	6.2
- Muscles pain	5	6.2
- Malaria	5	6.2
- Hypertension	4	5.0
- Flu	4	5.0
- Dizziness	4	5.0
- Preoccupation/ Anxiety	4	5.0
- Depression	3	3.8
- Sore feet	3	3.8
- Diarrhoea	3	3.8
- Weight loss/Growing thin	3	3.8

Many (51%) participants said they consulted a health professional but did not get any treatment. Inversely, some (43.5%) participants said they did not consult a health professional, but reported being treated. This is because seeing a health professional provider in Kinshasa doesn't necessarily mean receiving medical treatment since patients usually are given prescription to buy medications, and, for the most part, they are not able to buy medications because they can't afford them. In addition, self-medication is a common method of treatment in Kinshasa. This explains why 43.5% of the participants did not consult a health professional, but considered themselves treated. The dangers of self-medication are that one can take a medication that is not appropriate for treating the disease and there is a risk of overdose.

As shown in Table 9, a large majority (65 %) of the participants experienced more than one symptom or disease: only 6.3 % had no medical condition; 28.8 % mentioned only one medical condition; 31.1% mentioned two, 25% mentioned three, and 6.3%

mentioned four symptoms/diseases at the same time. A small proportion of the sample (2.5%) said they were suffering from at least five symptoms/diseases simultaneously.

Table 9: Number of medical conditions experienced by caregivers

Number of medical conditions	n = 80	%
0	5	6.3
1	23	28.8
2	25	31.3
3	20	25.0
4	5	6.3
5 +	2	2.5

All the participants also reported that they have been diagnosed as HIV/AIDS positive themselves. At this stage, it is difficult to say if the symptoms/diseases experienced by the participants are opportunist infections related to their HIV/AIDS positive status or if they are only a result of their caregiving burden. It is likely that both must have something to do with them.

The quantitative part of the study has one major limitation. The research is essentially based on self-reported health conditions and the data are consequently subject to reporting errors of unknown or intentionally unreleased medical conditions.

5.4. Challenges informal caregivers face in dealing with their health problems

The challenges of the participants are enormous. Not only do they have to take care of their husbands without enough help, but they are also isolated. They feel their family, neighbours and friends have abandoned them. They have no support and Sacome+ does not help them enough. Their children do not go to school and they do not have any hope for the future. Only 37% of the entire group of the participants reported receiving some type of formal medical treatment.

Several participants said they had received treatment for opportunistic infections or diseases. Most participants used herbal remedies (or African plants with the possibility of healing properties) for treatment because they cost less than pharmaceutical drugs and

can be easily found around the Kinshasa area. A few of the caregivers (7%) said they received only spiritual treatment. Little difference was found in access to treatment across the categories of socio-economics status. None of the participants used the conventional treatments for HIV/AIDS that are available in developed countries, such as antiretroviral therapy.

Participants were also asked about the condition of their living arrangements. The results indicate that a substantial proportion (76%) of the participants live with their husband either in a rented house or with their own extended family, their husband's family, or friends. The results also show that none of the participants have good living conditions, which aggravates their difficulties.

The participants were asked their opinion about the services at Sacome+. Many of them expressed their satisfaction with the way Sacome+ works and assists them. Although most of them thought that Sacome+ should do more than what they are currently doing. They clearly stated that the quality of Sacome+ services alleviated their suffering to some extent. Participants particularly noted the value of the food and nutrition considerations that have been integrated into HIV/AIDS programming and the steps that have been taken to reduce stigma and protect participants.

The participants added that belonging to the Sacome+ HIV/AIDS program has many advantages. It has not only helped them become genuinely interested in HIV/AIDS testing and understand the necessity of changing sexual behaviour, but the program has also taught them how to provide care, has provided them with some supplies (food, medications, etc.), and it has made them feel that they are contributing to society. A small proportion of the participants reported that the support from the Sacome+ was insufficient and is not adapted to their needs.

Chapter 6: Qualitative findings

The quantitative results provide a valuable, basic foundation of information about the context and the problems of informal caregivers for husbands living with HIV/AIDS in Bumbu. This chapter on the qualitative findings will complete our quantitative findings by illustrating the multiple ways that caregiving for husbands infected with HIV/AIDS affects women's health conditions, identifying the process of becoming an informal caregiver; and the perceptions of the problems and challenges facing informal caregivers.

The current chapter also explores the participants' opinions about how to address their difficulties and, therefore, change the quality of an informal caregiver's life. Participants' opinions on this matter will be compared to those expressed by Sacome+ staff and key informants (health planners, policy makers, civic leaders) from the Bumbu zone.

For the record, an ethnographical orientation was incorporated. Focus groups and semi-structured interviews (during which observations were recorded) were employed as the method of data collection. Even though probes and prompts were judiciously chosen t[illegible]aintain an open-ended interview structure, guidelines were also used to facilitate the d[illegible]ussion. Each of the participants was made comfortable enough to freely share his/her story. After each interview and focus group discussion, the researcher informally discussed his observations with staff and key informants to ensure an accurate interpretation of the observations. The rigour of the methodology was sustained and findings are presented as completely as possible.

Using the transcripts, field notes and information recorded, the researcher identified emerging themes, sub-themes, categories and patterns before interpreting the findings. Although similar principal themes and sub-themes emerged from the data from both groups, findings from the caregivers' focus groups and the interviews and focus groups with staff and key informants are presented in two sections. The first section addresses the content, themes and sub-themes that emerged from the caregivers' focus group discussion. The second section describes and analyzes the context and results of the staff' and key informants' interviews and focus group discussions.

6.1 Content analysis of caregiver interviews and focus group discussion

The content analysis of the focus group discussion with the caregivers revealed the following major themes and sub-themes: the process of becoming an informal caregiver; informal caregivers' perception of the caregiving role; sources, types and limits of support; caregiving burden and its impact on caregivers' health condition; caregivers suggestions for alleviating suffering of informal caregivers.

Table 10: Major themes and sub-themes from interviews and focus group discussions with the caregivers

Process of becoming an informal caregivers
- Love and sense of family responsibility - Lack of the choice for an alternative medical treatment - Feeling of isolation
Participants' perception of their caregiving role
- Disappointment - Bad and stressful experience - Stigma and ostracism - Lack of preparation and information - Poverty - Poor health
Types, sources and limits of support provided to caregivers
- Formal and informal support - Extended family/relatives, friends, neighbours, religious leaders/people, etc. - Spontaneous and solicited support - Insufficient and maladjusted support
Caregiving burden and its impact on the caregivers' health condition
- Negative impact that leads to many illnesses - Stressful lives
Participants' suggestions for alleviating caregiving burden
- Prevention measures (counselling, etc.) - Medications, children's schooling - Support measures for palliative care for infected people - Relief from general poverty: food, community housing, etc.

6.1.1. Process of becoming an informal caregiver

How come you must take care of your husband, can you relate how all of this started? That was the first question at the beginning of the focus group discussion with caregivers. The objective of asking this question was to let participants describe their own situations and to compare their stories and experiences. Three major sub-themes were

identified at this level: love and sense of familial responsibility, lack of choice for an alternative medical treatment, and feelings of isolation.

With respect to love and sense of family responsibility, it is very important to underline that nine of twelve caregivers participated in the focus groups discussions are still living with their husbands and three have their husband hospitalized. All of them repeatedly reported that love and sense of family responsibility was the determining factor for deciding to become an informal caregiver. Here is, for example, what a couple of them did have to mention:

> *"At the beginning, I did not know that my husband had HIV/AIDS. He had a fever almost every day, but all the fever medications could not stop his fever. Then the headaches and the cough began. I was anxious to keep my husband's health condition a secret. I did tell my husband's family and his boss since he could not go to work anymore. My husband's family helped me to take my husband to the hospital for medical exams. When the time came for the doctor to reveal the results of the medical exams, he refused to talk in my presence. He said I could only talk to your husband and his family and they would decide whether or not to tell me. I left the doctor's office and went back home, because I could not stay there. When my husband and his family (older brother) came back home, they lied to me saying that my husband was suffering from malaria. We bought anti-malarial drugs, but nothing changed. Progressively, everyone from my husband's family was disappearing while my husband's health condition was getting worse. One night, I asked my husband what was going on exactly because his malaria was not getting better and his family was not coming by any more. Seeing all that I was going through without any help, my husband felt sad and opened his heart to tell me the truth by saying, "Don't worry about me. Don't do anything else because I will never survive." He added, –"I am condemned to die because I was diagnosed as being infected with HIV/AIDS. I am sorry to tell you that now and forgive me. You can leave me if you want; I am not going to blame you. Remember only one thing that I love you." I was disappointed and shocked; I cried a lot [cries and pause]. I asked myself what to do. Should I leave him alone or not? I thought of*

my children, and I decided to stay with him because I still loved him. I also thought that leaving my husband alone would never solve any problems. Since nobody was there to take on my responsibility, I took over my family responsibility in a positive way. I said, "I am not giving up on my loved (my children and husband) ones." (Participant #3)

"My husband was a military commander. When he came back from a mission, he had fever, cough, diarrhoea, and headaches at the same time. His supervisor took him at the military hospital where he was diagnosed as being infected with HIV/AIDS. Nobody told me that. After three months, my husband received a letter from his supervisor saying, without any explanation, that he was no longer a commander and we must leave the military house. I went to see his supervisor to ask why he was trying to get us out while my husband was sick. My husband's supervisor asked me if my husband hadn't told me anything about his medical situation. I said no, and his supervisor told me, "Madam your husband has HIV infection. The army doesn't need his services anymore, so you must leave the military camp." Because I loved my husband, I decided to take care of him. I also decided to ensure that my children would always be taken care of." (Participant #7)

Lack of choice for alternative treatment was the second factor that dictated participants' decisions to become informal caregivers. In the excerpts below, four of the twelve participants recount their experiences:

"After finding out that my husband was infected with HIV/AIDS, I told him that there was no point for him to keep taking malaria medications. We needed to look for something that would be more appropriate for his medical condition. At that time, I did not know that HIV/AIDS is not treatable. We went to consult a doctor at the Kinshasa General hospital. We were told that there was nothing they could do for my husband. Instead, the doctor told my husband to keep treating the opportunistic diseases. I could not believe my ears. I took my husband somewhere else and I was told the same thing. At this point I came to realize that there was no one who could help me. I decided then to keep my

husband at home and care for him myself with the traditional herbal treatment." (Participant #1)

"We tried to get the medications for my husband. We were told that Tri-therapy is very expensive and hard to handle. We could not afford it, I asked how expensive Tri- therapy was, and when I heard how much it would cost, I immediately understood that we don't have that money to get my husband access to Tri- therapy, so I took him home." (Participant #4)

"My husband was hospitalized. After two weeks, it became difficult to pay the hospital fees. We did have outstanding fees to pay. A nurse came to tell me that the hospital needs money. If we cannot pay, we better go [long pause] home. I did not have any choice, so I decided to go home with my husband." (Participant #9)

"Infected with HIV/AIDS, my husband also developed tuberculosis. He was put in quarantine. The worst of it was that nobody was going to check on him [cries]. He was treated like an animal. After four days, I said to myself if I leave my husband in this situation, he is going to die in few days. I took him home where with members of my church we take care of him as we can." (Participant #12)

Isolation, caused by stigma and ostracism, was the last factor that led participants to take on their husband's care at home. Two of them affirmed this:

"Since every body not only left us alone, but also did not want to see us or even to hear from us, I could not leave my husband dying, quietly but surely, alone. That's why I am taking care of him." (Participant #2)

"Having HIV/AIDS infection in Congo is like being a dangerous criminal, so soon as my neighbours and relatives heard about my husband's sickness, they concluded that [stammering] no one in my family could be visited. I had then to do something for my nuclear family." (Participant #10)

6.1.2. Participants' perception of their caregiving role

The second question, "How do you find your caregiving role for your husband, your children and yourself?" was asked to obtain participants' perception of their caregiving role.

Based on the frequency of participants' responses, the perception of their caregiving experiences as informal caregivers is negative. In general, most participants have been disappointed by the community's (family, friends, etc.) reaction to their husband's sickness and found caregiving a difficult job to handle. According to what they said, four factors explained their negative caregiving experience: stigma and ostracism lack of preparation and information, poverty, and their own unhealthy condition. Below is what several stated:

> *"How can it be easy if you have to do everything by yourself? Besides, you have nothing [sad smile], and you have been diagnosed as being infected with HIV/AIDS yourself?"* (Participant #3)
>
> *"Like now I haven't eaten yet since yesterday, but I have to care for my husband. I have to find some food for him because if he doesn't eat, it will affect him a lot. On the other hand, my children must eat too, but I have nothing to give them. Can somebody live with all of this stress [cries]?"* (Participant #6)
>
> *"I am sick myself. I have no access to medical treatment and nobody cares, but I always have to be there for my husband and children. This is not helpful at all."* (Participant #7)
>
> *"I cannot help my husband one hundred percent since I have to first think about my own medical condition. [Long pause]... I think my husband is somewhat lucky to have me. I wonder if anyone will help me like that. My children are still too young to care for a sick person, so they will not be able to help me out. You see, when this comes to mind (and it does all the times), I feel like I have to give up and kill myself. In that context, how can it be easy to take care of my husband?"* (Participant #9)
>
> *"My husband had three wives. I am his first one. He married the other two only a year ago. At that time, he was not aware of his seropositive HIV/AIDS status. When all of us knew it, my husband's two last wives left us*

leaving behind them two little kids they had with my husband. I now have to look after my own children, my husband and those two little abandoned ones. Can you imagine how hard it can be?" (Participant #11)

"We were living the same area with my fiancé. During our engagement, my family told me to get the HIV/AIDS test done for both of us before the consummation of our relationship because my fiancé had a bad reputation for having many girlfriends at the same time. I did not do so. For me there was no point in doing it since I had already consummated my relationship with him. I lied to my family that I got my fiancé do the HIV/AIDS test and every thing was fine. My family consented to let me marry him with this misinformation. Now they know that my husband is diagnosed with HIV/AIDS and they know that I lied to them about the HIV/AIDS testing. They said I have to live with the consequences of my lies. Let me tell you that it is worse than being physically killed." (Participant #12)

6.1.3. Sources, kinds and limits of support provided to caregivers

In this study a distinction is made between formal and informal support. Formal support is provided by the Congolese government, local, national or international agencies that address issues relating to the prevention and treatment of HIV/AIDS. Informal support is the support caregivers receive from people they have "close relationships" with. This includes the extended family (or relatives), people from their church, husbands' professional colleagues and friends.

According to the participants, the only formal support they receive comes from Sacome+, but the sources of informal support varied. As it is shown in Table 11, six caregivers declared not receiving any informal support at all. One caregiver described her informal support system comprising only extended family or relatives, whereas three caregivers spoke of extended family or relatives, religious leaders/people, husbands' professional colleagues and friends constituting their supporters. Finally, two specified having only friends as sources of informal support.

Table 11: Sources of informal support

Number	Support	Sources
Six	No	- None
Three	Yes	- Extended family - Religious leaders/people - Husband's professional colleagues and friends
Two	Yes	- Friends
One	Yes	- Extended family

All of the participants felt that the support (informal or formal) they get is either insufficient or not necessarily adapted to their needs. However, they mentioned receiving several kinds of support including emotional and affective support, material support, financial support, medical support, informational support, physical support in the execution of caregiving tasks, etc. Moreover, although the informal support the caregivers received was both spontaneous and solicited, the formal support was only solicited. Spontaneous support was given without any request from the caregivers. Two caregivers reported that the informal support they were given was given out of sympathy for them, and they did not ask for it.

"I was suffering in silence. No one from my entourage (family, relatives or friends) knew what was wrong with my husband. By seeing my husband not going to work and by watching me doing all the jobs myself, they felt sad for me and realized that I could need help because it was hard. They found out by themselves that my husband became sick and could not go to work. It even became difficult to pay our rent, so we were having lots of tension and problems. Money, food, medication, school for children, etc. became a very big problem. That's why on their own they did start helping me." (Participant #1)

"One day I was crying with my three kids. My husband was laying flat and could not even move his legs. I did not know what to do or where to go, so I started crying loudly. My neighbours heard me and called for my mother. Instead of coming alone, she came with one of my best friends. When they got to my place, they just looked at me and said 'why are you killing yourself without

asking for any help?' I did not say anything, I just kept crying. Spontaneously, they went on by doing what was required to help me." (Participant #5)

Even though participants perceived the spontaneous support as reassuring, they also thought that, since they did not request the help, the spontaneous could not (and did not) fulfil all their needs.

Caregivers also approached Sacome+, their relatives, friends or husband's professional colleagues/employer to receive solicited support. Because participants did not know what to do after the HIV infected husband's seropositive status was diagnosed and known, they decided to seek help. The decision to seek help was difficult since participants did not wish to have their husbands' medical status known by several people. According to participants, it was impossible to solicit support without a disclosure of their husbands' seropositive status.

More than anything else, it was impossible for the participants to lie and get the specific help they were looking for. One of them clearly said:

"At the beginning, we were hesitant to approach anyone. We were worried that they would turn against us, and some of them (despite their social rank) actually did. Because of that, we still feel hurt and angry. We received some help from people but they were negative and judgmental. We could not even lie because the help we were seeking would lead to questions, which required us to tell the truth. Since we were in need, we did not have choice. We had to take the risk of being truthful even when we were not sure how the person would react. That is why I can say our action of seeking for help was led by a hope that coexisted with shame and humility. Otherwise, we could not do so." (Participant #8)

6.1.4. Caregiving burden and its impact on caregivers' health condition

The discussion led us to the third question formulated as follow: "Did your caregiving role change your life? If so, please tell us in which points of view and how? The purpose of this question was to understand from the participants' perspective if their caregiving role affects their life, especially their health condition.

Participants pointed out that women's lives are negatively impacted by caregiving burden. Not being able to participate in social activities, to work and to enjoy life were reported by caregivers to be the direct disadvantages of their informal caregiving. More often, participants mentioned experiencing a lot of illness (see chapter 5 on the quantitative findings) since they became caregivers for the HIV/AIDS infected husband. For instance, two participants stated exactly this:

> *"Before, I never came down with all these diseases I have now. I almost never got sick before. Since I am doing all of this for him [meaning the husband], it looks like I am even more sick than him."* (Participant #4)
>
> *"You know what, I have been out of my mind since I started caring for my husband. Knowing that this will end when he dies, I always have headaches, stomach-aches and anorexia. I don't think I will ever get well again in my lifetime. Don't forget that I am seropositive myself."* (Participant #6)

Unfortunately, it cannot be known whether the caregivers' health problems were related to their own HIV/AIDS, or to the burden of caregiving. However, the qualitative data supports the argument that the participants health status has been negatively impacted by their caregiving role.

6.1.5. Participants' suggestions for alleviating caregiving burden

What do you think should be done for you or for anyone else who is caring for a husband with HIV/AIDS?

Participants suggested many measures that should (and need to) be taken to alleviate their suffering as informal caregivers. Those measures include prevention, alleviating poverty (providing food, community housing and medical supplies) of HIV/AIDS careguvers, supporting children's education, palliative care for infected people and psychological support. Most participants also would like to have continuous services from Sacome+ rather than being helped only twice a month or in emergencies.

On the other hand, caregivers also stated their concerns that some Sacome+ staff don't have the required skills to help them, so most participants stressed that Sacome+ staff should have better education.

Confidentiality is still a very big problem for most participants. They asked that Sacome+ keep the information about their husband's sickness secret. This would help to avoid the stigmatization and ostracism that they frequently experience. Another issue caregivers raised was that the public should be aware of HIV and the implications of the disease to prevent the spread of the epidemic.

6.2. Interviews and focus group discussion with Sacome+ staff

The goal of the interviews and focus group discussion with six Sacome+ staff members (three men and three women) was to get their opinions about what the main problems are for women who care for their HIV/AIDS infected husbands and about the Sacome+ activities and how this could be dealt with using a gender sensitive approach.

The content analysis of the focus groups and the interviews with Sacome+ staff helped us to identify several themes and sub-themes, which are given in the Table 12 below.

Table 12: Themes and sub-themes identified in the interviews and focus group discussion with Sacome+ staff

Caring for a HIV/AIDS infected husband is a big responsibility
- Husbands become very dependent on their wives - Caregivers were not prepared to their jobs and don't have enough skills - Caregivers don't always take care of themselves - Caregivers don't necessarily work to have a positive attitude toward caregiving
An informal caregiver is an important partner on the health care team
- Caregivers work as members of a team and play a huge role - Caregivers establish good relationships with professional health care providers - Caregivers work to try to solve problems
Sacome+ activities at least attenuate people's suffering and prolong their lives
- Sacome+ activities cannot be abandoned - Those activities should be done by people with the required skills and those people should receive good pay

6.2.1. Caring for a HIV/AIDS infected husband is a big responsibility

All the Sacome+ staff members recognized that their patients' wives have a very big responsibility in taking care of their HIV/AIDS infected husbands. At the same time, they also underlined that they hear daily from caregivers that caregiving can have important benefits to the caregivers. For instance, they said that some caregivers have considered that caring for their husband has given them a sense of satisfaction and confidence. They have been given the opportunity to show that they can be useful.

"Helping a loved one with a serious illness such as HIV/AIDS is a big responsibility, especially as the illness progresses. In the majority of our cases, the husband whom the wife is caring for has become very dependent on her. It is an especially big responsibility when we know that those women (caregivers) don't have the help they need to do their job."

"Since all of our patients know that they are going to die sooner or later, their wives are their only reason for living. I'm sure that if their wives were not helping them the way they do, many of our patients would not still be alive today. When they can, wives provide food, drink, psychological and affective support, etc. No one else could do the same."

"Sometimes, patients refuse to talk to us. Their wives help us to get them talk and develop a good relationship with them. Often, patients tell their wives to respond to our questions to them because it looks like they don't trust us."

"The thing is they [caregivers] have never been prepared for their role and don't even have enough skills to handle their tasks, which is a risk because it happens that they have to act like us [health professional providers], especially at night."

"I don't think caregivers realize how big their responsibility is because they don't always take care of themselves. I know that they don't have the means to do so, but it seems like they have lost the sense of purpose in their lives. Some of them sometimes express the feeling that they have given up on everything."

"I know that caregivers are facing a lot of problems, but while they all need to emphasize the positive aspects of caregiving, instead they don't necessarily try to maintain a positive attitude toward caregiving. They never

cease to complain about their situation. However, some of them do consider their job as a successful exercise, and they see it as being helpful to someone they love and care deeply about. Others feel that caregiving has enriched their lives. Some caregivers see it as a challenge and as an opportunity to do the best job they could ever have done in their lives. Still others see caregiving tasks as a way of showing appreciation for the love and care that they have received themselves from their husbands."

6.2.2. Informal caregiver is an important partner on the health care team

The Sacome+ staff members concluded that the importance of the caregivers' role made them become major partners on the health care team.

"Because good caregiving for our patients requires a team of people with different skills, interests, dedication and perspectives, everybody (physicians, nurses, social workers, volunteers, friends, family members and religious leaders/people) makes important and unique contributions to care. Among those people's contributions, family members, especially wives, are making a very special contribution that facilitates our work with the patients. They have a close, personal relationship with the patient that we don't have, so they play a key role in involving the patient in their care."

"As a health care team member, the caregivers make our job easier by working cooperatively with us and other members of the care team in solving caregiving problems. All of them have established a good relationship with health care providers. This of course leads necessarily to better care for their husbands and less stress for themselves."

"What is awesome is that since I have been working here (for Sacome+), caregivers have been considering us as a good resource for information about their husbands' medical conditions. They think that we do help them to understand their husbands' current health status and what to expect in the future."

While the discussion was taking place, a patient just vomited in front of us. His wife had immediately to mop the floor and wash his face. Instantaneously, a Sacome+ staff member said:

"See how hard caregiving is? It is a 24-hour job. Caregivers must be ready to do something for their husbands all the time. I think you understand now why we said that caregivers play a huge role. With all of this they don't get enough help. The world is not fair."

At the end of our discussion, all the Sacome+ staff expressed the belief that, in general, the caregivers they deal with are good and therefore supportive caregivers for their husbands. In the opinion of Sacome+ staff, the caregivers communicate effectively with their husbands, they always are there to give support, they work with health care professionals, work with others who also care about their husbands and they somehow take care of their own needs and feelings in order to be one hundred percent in their husbands' service.

6.2.3. Sacome+ activities alleviate people's suffering and prolong their lives

Staff members of Sacome+ believe that they don't do much, but at least their activities help to attenuate caregivers' suffering and somehow improve the social condition of people living with HIV/AIDS.

"Can you imagine if Sacome+ was not there, what would happen to those people [clients and their family]? Our government never cares; they fight for the power, not for the well-being of the population. We do everything without receiving a decent salary."

"Sacome+ would do more than what it is doing now, but we have the merit of doing what people are afraid of: helping and working with HIV/AIDS infected people. Without Sacome+, none of our clients would receive any help at all and everyone knows that."

"In the majority of the cases, our clients have only Sacome+ as support. Their family and friends have abandoned them. Where would they get food if Sacome+ were not providing it? They no longer work because of their sickness and their wives cannot work either because they are caring for their husbands. I

bet that many of them would already have died or killed themselves if Sacome+ was not doing all of this for them."

6.3. Key informant interviews and focus group discussion

The researcher used the following questions to lead the discussion with the key informants: Could you tell me about your experience as (position) at the zone of Bumbu? Do you think that the Sacome+ is useful? If yes how and if no why? In your opinion, is there a need for extending services at Sacome+? Why? Sacome+ offers many services. Which one(s) is or are not appropriate for the affected families?

The answers provided to these questions allowed the researcher to come up with several themes and sub-themes. In general, key informants agreed that even if Sacome+ is doing a good job, it does not have capacity to meet all the needs of those who are without service. For them Sacome+ is very useful, but there is still a need for further development of the program.

"There are a lot of gaps between what we know is needed and the services provided" (The chief doctor of the Bumbu Zone).

Key informants expressed the need for improving and extending the existing services at Sacome+. For them, there are major barriers that include lack of funds and the absence of political will from the government. This was frequently mentioned as the main cause of the situation.

"There is a lot that could be done to develop the services given to HIV/AIDS people and their families in terms of infrastructure, service provider training, medical supplies, etc. But nobody cares."

Key informants also stressed that there is a high level of stigma associated with HIV/AIDS.

"Most communities still make moral judgements on people living with HIV/AIDS and on their families. Consequently, individuals' fears regarding confidentiality are particularly strong. That is why we think that the need for

ensuring cultural sensitivity, language, and sensitivity to beliefs and values attended to in the services delivered by Sacome+ is more than essential. Because patients and their families have the perception that staff can spread the content of their files behind their backs, confidentiality must be the principle that leads Sacome+ actions."

"Problems that make the work at Sacome+ difficult are that health care providers often lack skills and sensitivity with regard to HIV; there are inadequate resources and lack of money; HIV/AIDS patients are often not able to secure the medications they need; patients lack transportation to get to the Sacome+ centre, etc." (Municipal authority in charge of Health).

Chapter 7: Discussion, Recommendations and policy implications

In this final chapter the results of the study are discussed and several recommendations are made to alleviate the suffering of the women as informal caregivers of the husband living with HIV/AIDS and to ameliorate the quality of life for those caregivers infected with HIV/AIDS. The policy implications for these recommendations are also discussed.

7.1. Discussion

The section addresses the three principal research questions: What are the problems faced by women as informal caregivers for husbands living with HIV/AIDS? Among those problems, which ones influence the women's health status and how? How do women deal with those health issues and what support mechanisms both present and absent would mitigate the impact of HIV/AIDS on these caregivers?

7.1.1. Problems faced by women as informal caregivers for husbands living with HIV/AIDS

The study revealed that three main factors dictated participants' decision to become informal caregivers for husbands infected with HIV/AIDS: love and sense of familial responsibility, lack of choice for an alternative medical treatment, and feelings of isolation.

Both quantitative and qualitative findings highlight that the women as caregivers in Kinshasa play key caregiving roles and will continue to play these roles in caring for their husbands who are living with HIV/AIDS. As a consequence of these responsibilities, the study discovered the following problems faced by these women.

The women caregivers faced major difficulties with regard to the provision of HIV/AIDS-related services included lack of money, medications and food. Schooling for the children was also described as one of the big problems that women have as informal caregivers. As many other studies have noted, "a direct impact of AIDS is to diminish mobility, decreasing available economics resources" (McGrath et al., 1993, p. 63).

Most of the time, caregivers have to bear the bulk of the responsibility for the care and support needs of their husband, and experience considerable burden and adverse health effects.

The majority of the caregivers lack appropriate housing: 31.2 % of them were renting their house and 68.8 % couldn't afford rental fees. They live either with their family, with their husband's family or with a friend, in the community house, in the military Camp, in the Home Care Program Centre or in the church. This corroborates Knodel's (2000, p. 494) results from his study where he also found that good housing constituted a major issue for people living with HIV/AIDS and their families in Thailand. He mentioned this about caregiving and living arrangements: "...a substantial proportion of persons with AIDS move back to their communities of origin at some stage of the illness. Two-thirds of the adults who died of AIDS either lived with or adjacent to a parent by the terminal stage of illness and a parent, usually the mother, acted as a main caregiver for about half."

Participants complained about being victims of a high level of stigma and ostracism from their friends, neighbours, relatives/family, etc. This is not a surprising since many other studies have shown that, in Africa, people infected with HIV/AIDS and their families often are stigmatized and ostracized (Aggleton, 2000, Hansen and al, 1998). In addition, health care providers often lack skills and sensitivity with regard to HIV/AIDS.

All of the women mentioned that, since they have become informal caregivers, they have not been able to participate in social activities, to work or to enjoy life.

Inadequate resources stand in the way of providing services and support. Contrary to Knodel (2002, p. 490) who found that "even when a parent is a main caregiver, other family members, particularly ... adult children, often assist the parental caregiver," our study underlined the lack of support from any other family member in the majority of the cases. Knodel (2002) also found that sympathetic and supportive reactions in the community were more frequently reported than negatives ones. This was not the case for our study.

Finally, participants are also worried about their children's future because of the possible HIV/AIDS positive status of their children and the difficulty in paying for their children education.

7.1.2. Problems that influence caregivers' health condition

Informal caregiving entails a lot of responsibility. Since participants were not prepared for doing that kind of work, they now experience considerable burden and many health problems. The main health problems experienced by caregivers are headaches, gastritis/stoma aches, vomiting, fever, anorexia and stiffness.

Most of the participants also reported low levels of overall happiness. The majority of them had more than one health problem. These results are not different from what was previously found by Kespichayawattana (2002, p. 503): "Many parents with HIV/AIDS infected children experienced anxiety, insomnia, fatigue, muscle strain, and head and stomach aches during the time they cared for their ill children, and many experienced these problems often." All of the caregivers in this study are also infected with HIV/AIDS, anticipate a lot of suffering and don't believe in their future.

Since we could not find any other African data regarding health of caregivers, we were not able to compare our findings with similar situations. As a result, we have been unable to state if the low level of the caregivers' health is caused specifically by the caregiving burden or by their positive HIV/AIDS status.

7.1.3. Mechanisms of support and participants' strategies of dealing with their problems

In general the participants' situation is a tragedy. They have a negative opinion of their caregiving role/experience because either they feel they are not getting help or they are getting some help that is not enough and/or not adapted to their needs. For the majority of caregivers, there is no support available. They feel abandoned and do not know which way to turn. They do not even have any strategy for coping with their day-to-day work. All they do is to pray and to go to the Sacome+ centre for seeking help.

In addition, the study discovered that only a few of the participants get both formal (specifically from Sacome+) and informal (provided by the extended

family/relatives) help. According to what they mentioned, those participants who did receive support received many kinds of support including counselling, food and medications.

Participants did point out several strategies that could be established to alleviate their suffering. In their opinion, those strategies included preventing HIV/AIDS, alleviating poverty, supporting children's education, providing palliative care for infected people and offering psychological support for caregivers. Most participants also suggested that continuous services from home care rather than being helped only twice a month or in emergencies cases would alleviate some of their difficulties.

7.2. Recommendations and policy implications

The study reveals that HIV/AIDS in Congo constitutes a tragedy for affected households. Since helping informal caregivers necessarily benefits both the informal caregiver and the patient, the findings from this study have implications for intervention. The response should focus on six principal areas: the central role of the Congolese government, mass education, revalue of hospital and community services, improvement of nutrition and living conditions, child protection, and rapid testing and early treatment.

7.2.1. Central role of the Congolese government

The findings from this study have shown that unfortunately official policies in Democratic Republic of Congo provide limited options for caregivers support from formal sources. This in return has increased the roles and responsibilities of informal caregivers, particularly for the wives of men infected with HIV/AIDS.

Because of this, the Congolese government has a crucial role to play in establishing urgently needed programs to support the considerable and perpetually growing number of informal caregivers. This means that there is an urgent need for the development of various informal caregiver services in Congo. These must include counselling services, the provision of material and financial assistance, and the creation of support groups and respite care services.

Those services would assume a significant role in Congo because of the stigmatizing nature of the HIV/AIDS infection, which limits support seeking from

informal sources and, consequently, informal caregivers are left to fend for themselves. The extent to which these needs are recognized and responded to remains questionable in the light of a long lasting ongoing civil war and insecurity.

7.2.2. Mass education

The findings of this study suggest the importance of educating the general population in Congo about HIV/AIDS and sensitizing them to the consequences of HIV/AIDS. Such endeavours would have two advantages. They would provide knowledge about the infection, thereby dispelling myths and misconceptions, and they would also provide descriptions of the demands and impact of HIV/AIDS. With this information, members of the Congolese community would be less likely to withdraw from informal caregivers (as well as from the HIV/AIDS infected person) and less likely to provide negative support (discriminatory attitude, etc.). Instead they would be more likely to rally around them.

The research also shows the need for the Congolese government to address HIV/AIDS as part of a comprehensive program that also deals with poverty, promiscuity, and lack of education. An education program against the fight against HIV/AIDS is very important since the Congolese culture has a deep impact on the success of prevention programs.

The values surrounding promiscuity, polygamy and endogamy, have a significant influence on the perceptions and sexual behaviour of Congolese people. In substance, the sexual aspect of life for Congolese people is sacred and the behaviour in this matter is very restricted. For every ethnic group in Congo, discussion of sexuality is taboo. Sexuality is viewed as a private matter or a reserved domain of the individual's or the couple's intimacy, although it also concerns the family (in the sense of membership in an extended domestic group or in a system of relationships) in its aspects related to procreation and to the social field (power, alliances). Consequently, questions about reproduction and sexuality remain family business.

That is why, traditionally, there has been no official sexual education in Congo. In Congolese tribal society, sexuality constitutes a sacred domain and no one has the right to interfere in it. Thus, people are poorly informed about family planning in general and

contraceptive methods in particular. For example, Congolese people are familiar with condoms and their use, but there is mistrust of their use, notably by the "elders" who are guarantors of the moral order. This mistrust is probably connected with the beliefs of risks of infertility, infection or weakening of the virile force.

In Congo, some people still think that condoms are mechanical barriers, made by foreigners, to protect people from foreign troubles, which the foreigners generate. They also think that using or asking for a condom consequently implies distrust of the partner. Another major contributor to the spread of HIV/AIDs in Congo is that polygamy (having more than one wife at the same time) is a highly valued tradition. Another issue for several tribes is the traditional intra-vaginal practices, which all the young women must go through, e.g. clitoris ablation or excision, ritual scarification, etc. Finally, some Congolese tribes believe that sexually transmitted diseases are punishment from God and must be treated by the traditional practitioner, or by auto-medication, and must be kept secret. Thus, prevention and treatment are not seen as viable options.

The above shows clearly that, when it comes to the Congolese culture, developing a policy for prevention of risky sexual behaviour may be a challenge. While it supposes a better knowledge of the sexual activity of people, it cannot be dissociated from the analysis of the other factors. Fighting against cultural barriers that exist in Congo does not mean eradicating all the cultural practices. Doing so would lead to the alienation of those people whose cooperation is necessary for preventing the spread of HIV/AIDS. The big issue would be for the program of education to find the concepts, the actions and the ways that can at the same time integrate traditional Congolese beliefs with current AIDS prevention practices. These concepts, actions and ways need to be presented in a way that does not appear to threaten existing customs and lead to the corruption of tradition.

Even though an educational program should encourage abstinence from sex for unmarried persons specifically, in general, the program should find a way to distribute condoms to people (married or unmarried) as a protective measure against HIV/AIDS and other sexually transmitted diseases without attaching stigma to the use of condoms. The program should try to encourage abstaining from premarital sex, and fidelity in marriage to prevent sexual transmission.

From our observations of the way participants acted and by listening to their complaints, we would recommend that informal caregivers in Congo should learn more about what is helpful and unhelpful in their caregiving role. This implies that an educational program that distinguishes between helpful actions (which include expressing love or concern, acting naturally, providing an opportunity for reciprocity and providing encouragement) and unhelpful actions (like avoiding interaction, acting embarrassed or ashamed, breaking confidentiality, and criticizing their medical care decisions) would be beneficial for both caregivers and receivers of care.

Informal caregivers in Congo do not only experience difficulties. As a matter of fact, this research found that, while caregivers experience stress and depression, they also experience positive feelings associated with loving, caring and comforting. In order to sustain this positive well-being, we support the development of a program to make informal caregivers aware of what is personally meaningful and valued. It also would be interesting if that program could facilitate intimacy and conversation between informal caregivers and their partners. This would help informal caregivers maintain the positive feelings they have in what they are doing.

7.2.3. Revalue of Hospital and Community services

While home care should help to decongest hospital services, this research has revealed that, in Congo, it is becoming synonymous with inferior services because people are discharged from hospital back into the community without proper arrangements and planning. Already overstretched and under-resourced outreach services are expected to accommodate them. Home care also has a low visibility (many people do not even know that home care exists), which affects its utilization.

This study suggests that the government should take this problem seriously and invest enough money to hire well-trained staff for community outreach and home care programs. In addition, the government should establish a program that would contribute to promote home care and its services. This would help home care play a complementary role as opposed to being a substitute for adequate hospital care.

The study has shown that informal caregivers require psychological help (such as support groups) to help them cope with the emotional roller coaster involved in caring for

a terminally ill person. Informal caregivers also need support in grieving the death of a loved one since some of them are unsure how to act around an infected HIV/AIDS husband, or confused about the best way to finally show love and support.

For this, we would like to underline the urgency with which public awareness about HIV/AIDS should be created. Building up awareness would have many advantages. For instance, the community would be sensitized to the experiences of informal caregivers, and instead of discriminating against them, they would reach out to them. Inappropriate support would also be reduced or even eliminated. On the other hand, informal caregivers, being assured of an understanding and positive response, would be willing to come forward and seek support.

7.2.4. Improvement of nutrition and living conditions

The findings on the lack of food are also noteworthy. Many prior studies have shed light on the impact of AIDS on food security in highly impacted countries. They demonstrate that HIV/AIDS reduces food availability (through falling production, loss of family labour, land and other resources); access to food (through declining income for food purchases); and the stability and quality of food supplies (through shifts to less labour-intensive production) (Ward and Brown, 1994). None of the participants in this study participated in the paid labour force and the majority of them had an income of less than one thousand US dollars a year.

This corroborates that the effect of HIV/AIDS on households is profound. AIDS causes labour to be lost or diverted from production to care. Household incomes fall due to loss of wage earners and rising spending, particularly on medical care and funerals. AIDS also generates new poverty as people lose housing tenure and employment. A study in Zambia found, for example, that AIDS led to a rapid transition from relative wealth to relative poverty in many households. In two thirds of families where the father died, monthly disposable income fell by more than 80% (Kelli, 1997). Actions should be taken to improve Congolese quantity and quality of food.

An important finding in this study is that most participants need immediate housing assistance. With the growing number of the HIV/AIDS infected persons and the stigma from which these people and their families continue to suffer, there will be an

increasing need for housing assistance. To solve this problem, and at the same time anticipate its consequences, the government should take into account the possibility of establishing safe, stable, affordable and medically appropriate housing for people living with HIV/AIDS and their families.

According to our findings, in addition to being well-trained, the counsellors in the home care program require professional support by supervisors, which could make a substantial improvement to the counselling component.

7.2.5. Child protection

Young children being HIV/AIDS infected during pregnancy of the mother also seemed to be a major issue for the women in this study. All the participants have children and several of these children are less than 10 years old. Some of these children are already infected with HIV/AIDS, which emphasizes the need for educating women who are known to be HIV infected about prevention of mother-to-child HIV transmission. We believe as UNICEF that, "...irrespective of HIV infection rates, breastfeeding should be promoted, protected and supported. While the danger of mothers transmitting the disease to their children by breastfeeding is substantial, the risks involved in alternatives such as formula feeding are even greater. Health risks are high due to a lack of clean water in many poor communities. In some areas, a social stigma is attached to formula feeding because those who do not breastfeed are assumed to be HIV-positive. In addition to the health risks, the prohibitive cost of formula makes its widespread use virtually impossible" (UNICEF, 2003, p. 92).

The literature on children affected by AIDS is replete with observations to the effect that children "...in these circumstances suffer adverse psychological consequences and that they have a 'need for' or a 'right to' psychological support" (Schable and al., 1995 p. 513). A child whose mother or father has HIV starts "... to experience loss, sorrow and suffering long before the parent's death. And since HIV can be spread sexually between father and mother, once AIDS has claimed one parent, the child is far more apt to lose the other. Children therefore find themselves taking on the role of a parent-performing household chores, caring for siblings, farming, caring for ill or dying parents-creating stresses that would exhaust even adults" (Schable and al, 1995, p.514).

In human terms, the impact of HIV and AIDS on infected children poses serious threats to child welfare. The problems and needs of affected children are summarized as: "Psycho social distress, discrimination and stigmatization, increased malnutrition, lack of security, lack of parental guidance, loss of access to health care, including immunization, increased demands for labour, fewer opportunities for schooling and education loss of inheritance, homelessness, vagrancy, starvation, crime, exposure to HIV infection and other STDs and sexual exploitation, either commercially or at home" (Raveis and Siegel, 1991, p. 42).

7.2.6. Rapid testing and early treatment

Informal caregivers would also benefit from prevention education and assistance in staying HIV-negative. HIV-positive caregivers need information on early treatment of HIV in order to stay healthier longer. Greater attention should also be placed on rapid testing. This would help the person to start seeking for help earlier and planning her/his life activities in advance. This strategy offers great promise for getting hard-to-reach individuals to learn about their HIV status, because many of the Congolese living with HIV/AIDS do not know they are infected. Improved HIV surveillance techniques, particularly sero-surveys of key populations, are also critical for helping to understand the epidemic and better evaluate and target prevention services (World Vision, 2003). Anonymous testing is particularly important since stigma remains a significant barrier to accessing testing and care services.

The Democratic Republic of Congo is currently divided in many parts because of the ongoing civil war. All of our recommendations cannot be followed while government has so many preoccupations including how to stop the civil war. That is why we first are recommending a global political solution, since in the context of war very little can be accomplished by the Congolese government.

Conclusion

To our knowledge, in the Democratic Republic of Congo, the study of informal caregiving in general, and HIV/AIDS informal caregiving in particular, has remained a largely unexplored area. To this end, the present study has extended our understanding of the context of HIV/AIDS. We found that, in Congo, the situation of women who are informal caregivers for their HIV/AIDS infected husbands is dramatic. They carry the main responsibility for caregiving with very little support. At the same time, they are stigmatized and ostracized. We also found that these women are often in poor health themselves and question their own future because of their seropositive HIV status. These women also worry about the future of their children some of whom have already been diagnosed as being HIV infected.

The danger that HIV/AIDS and its negative effects represent bring up a large list of things that should be done in Congo, as well as in all the developing countries where HIV/AIDs infection is most devastating to people. Even though the financial, material and human resource constraints faced by these countries make that wish unrealistic because fighting HIV/AIDS is an enormous challenge, we do believe that the world is not and cannot be powerless to address it.

In the case of the Democratic Republic of Congo, this takes "only" goodwill, meaning a very strong political will. This study has formulated several recommendations that would help to alleviate the suffering of informal caregivers and improve the quality of life for HIV/AIDS patients' at the same time. However, because this is an exploratory study, additional in-depth research would likely provide valuable information for programs to use in designing effective interventions.

In this respect, future research on informal caregivers and their children after their husbands die would be helpful. This would include the establishment of several strategies to prevent women's and their children's longer term suffering. Also, research focusing on children's outcomes when they lose both of their parents from HIV/AIDS would be helpful.

Finally, stigma against people living with HIV/AIDS and their families is another cause of disaster for them. Unfortunately, that stigma comes from almost everyone, including health care professionals. A study on how to mitigate the stigma, starting with

heath care professionals would be a very big step in the fight against HIV/AIDS, since health care professionals are expected to play an important role in developing countries where most people are not educated, such as the Republic Democratic of Congo.

References

Aggleton P. HIV and AIDS-related stigmatization, discrimination and denial: Forms, contexts and determinants. Research studies from Uganda and India. *General Report*, UNAIDS, Geneva, Switzerland, June 2000.

Avis SW, Gregg RJ. & Scargill MH. *The Intermediate Dictionary.* W.J. Gage limited, Toronto, 1963.

Barer BM & Johnson CL. A critique of the caregiving literature. *Gerontologist* 1990; Vol. 30(1): 26-29.

Bloom J. Social support, accommodations to stress and adjustment to breast cancer. *Social Science Medicine* 1982: Vol. 16: 1329-1338.

Blainey NT, Goodkin K, Morgan R, Feaster D, Millon C, Szapoczlnik J. & Eisdorfer, C. A stress-moderator model of distress in early HIV-1 infection concurrent analysis of life events and social support. *Journal of Psychosomatic Medicine* 1991; Vol. 35: 297-305.

Bor R & Elford J. The family and HIV disease. *AIDS Care* January 1993; Vol. 5(1): 3-8.

Brown MA. & Powell-Cope G. *Caring for a loved one with AIDS: Renegotiating the Relationship.* University of Washington Press, 1992.

Bruhn JG. & Philips BU. Measuring social support: a synthesis of current approaches. *Journal of Behavioural Medicine* 1984; Vol. 7: 151-169.

Cobb S. Social support as a moderator of life stress. *Psychosomatic Medicine* 1976; Vol. 38(5): 300-331.

Cohen S. & Syme SK. *Social support and health.* Orlando: Sidney Academic Press; 1985.

Cohen S. & Syme SK. *Issues in the study and application of social support.* In COHEN S. & Syme SK. (Eds) Issues in the Study of Social Support, 3-22, Orlando: Sidney Academic Press; 1985.

Cohen S. & Willis TA. Stress, social support, and the buffering hypothesis. *Psychological Bulletin* 1985; Vol. 98: 310-357.

Congolese Minister of Agriculture, *Annual Report*, Kinshasa, 2002.

Congolese Minister of Social Affair and Public Health, *Annual Report*, Kinshasa, 2002.

Congolese National Institute of Statistics. *National statistics of population.* Kinshasa, *General Report*, 2001 and 2002.

D'Cruz P. *The family context of a terminal illness: The case of HIV/AIDS.* Unpublished doctoral dissertation. Mumbai: Tata Institute of Social Sciences (TISS), 1998.

D'Cruz, P. Engulfing darkness: The impact of HIVAIDS on the family. *Families in Society* 2002; Vol. 83: 416-430.

Desclaux A. 10 years' research in the social sciences on AIDS in BurkinaFaso. *Sociétés d'Afrique et sida.* Université de Bordeaux II, France, 1997; Vol. 7 (2): 127-134.

de Figueiredo RM. & Turato ER. Needs for assistance and emotional aspects of caregiving reported by AIDS patient caregivers in a day-care unit in Brazil. *Issues Mental Health Nurse* 2001; Vol. 22(6): 633-643.

Elswood BF. & Striker RB. Polio vaccines and the origin of AIDS. *Medical Hypothesis.* University of California (San Francisco) 1994; Vol. 120(4): 343-344.

Folayan MO, Fakande I. & Ogunbodele EO. Caring for people living with HIV? AIDS and Aids orphans in Osun State: a rapid survey report. *Niger Journal of Medecine* 2001; Vol. 10(4): 177-181.

Folkman S, Chesney MA & Christopher-Richards A. Stress and coping in caregiving partners of men with AIDS. *Psychiatric Manifestations of HIV Disease* 1994; Vol. 17: 35-53.

Frankel B. Gail & Turner R. Jay. Psychological adjustment in chronic disability: the role of social support in the case of the hearing impaired, *Canadian Journal of Sociology* 1983; Vol. 8: 273-291.

Hartung D. & Moix B. *Deadly Legacy: U.S. Arms to Africa and the Congo War.* Arms Trade Resource Centre, New York; 2000.

Health Canada. Conceptual Framework Subgroup on Population Health. *Towards a Common Understanding: Clarifying the Core Concepts of Population Health, A discussion Paper.* Ottawa: Health Canada; 1996.

Kane RA. & Penrod JD. *Family caregiving in an aging society: Policy perspectives.* Thousand Oaks, CA: Sage; 1995.

Kespichayawattana J. & Mark V. *Health impacts of co-residence with and care giving to persons with HIV/AIDS (PHAs) on older parents in Thailand.* University of Michigan Population Studies Centre Research, Report Number 02-527, September 2002.

Knodel J. & Mark V. *The impact of the AIDS epidemic on older persons.* AIDS 2002, 16 (4): S77-S83.

Kreutzer et al. Patient correlates of caregivers' distress and family functioning after traumatic brain injury. *Brain Injury* 1994; Vol. 8(3): 211-230; 1994.

Land H. and Hudson S. HIV serostatus and factors related to physical and mental well-being in Latina family AIDS caregivers. *Social Sciences and Medicine.* January 2002; Vol. 54(1): 147-159.

Marshall C. & Rossman GB. *Designing qualitative research (2nd edition).* Thousand Oaks, CA: Sage Publications; 1995.

Matukala NT. *Ethnic origin of women and procreator behaviour in Kinshasa.* Unpublished Master's thesis, University Catholic of Louvain, Louvain-la-Neuve, Belgium, 1996.

McGrath JW, Ankrah EM, Schumann DA, Nkumbi S. & Lubega M. AIDS and the urban family: its impact in Kampala, Uganda. *AIDS Care* 1993; Vol. 5: 55-70.

Morse J. *The principles of qualitative inquiry.* INT D560 course notes 2002, University of Alberta, Edmonton.

Morse J. *Qualitative Health Research.* London, Sage Publications; 1992.

Mulegwa Z. *The Aids Epidemic in the Democratic Republic of Congo.* Personal communication; Kinshasa, 2000.

Ndaba-Mbata RD. Home-based care of the terminally ill in Botswana: knowledge and perceptions. *Int Nurs Rev.* Gaborone 2000; Vol. 47(4): 218-223.

Neufeld A. & Harrison MJ. Reciprocity and social support in caregivers' relationships: Variations and consequences. *Qualitative Health Research* 1995; Vol. 5 (3): 348-365.

Noh S, CHANDARANA P, FIELD V. & POSTHUMA B. AIDS epidemic, emotional strain, coping and psychological distress in homosexual men. *AIDS Education and Prevention* 1990; Vol. 2: 272-383.

Nooan AE & Tennstedt SL. Meaning in caregiving and its contribution to caregiver well-being. *The Gerontologist* 1997; Vol. 37(6): 785-794.

Panos. *Triple jeopardy: Women and AIDS.* London: Panos Institute; 1990.

Pieters G. Gynécologie au pays des femmes cousues. *Acts Chair,* Belgium, 1972.

Poindexter CC, & Linsk NL. Sources of support in a sample of HIV-affected older minority caregivers. *Families in Society* 1998; Vol. 79: 491-503.

Quinn T.C. et al. AIDS in Africa: an epidemiologic paradigm. *Science* 1986, Vol. 234: 47-79.

Raveis VH & Siegel K. The impact of caregiving on informal or familial caregivers. *AIDS Patient Care;* 1991; 39-43.

Reinhard SC. Living with mental illness: Effects of professional support and personal control on caregiver burden. *Research in Nursing & Health* 1994; Vol. 17, 79-88.

Reinhardt V. & Roberts A. *The African polio vaccine-acquired immune deficiency syndrome connection.* Lancet, 1997.

Rosenberg PS, Biggar RJ & Goedert JJ. Declining age at HIV infection in the United States. *New England Journal of Medicine* 1994; Vol. 330: 789-790.

Sala-Diakanda MP. *Approche ethnique des phénomènes démographiques. Le cas du Zaire.* Université Catholique de Louvain, Louvain-la-Neuve, Cabay; 1980.

Sander AM, High WM, Hannay HJ & Sherer M. Predictors of psychological health in caregivers of patients with closed head injury. *Brain Injury* 1994; Vol. 11: 235-249.

Sarason IG, Levine HM, Basham RB. & Sarason BR. Assessing social support: the social support questionnaire. *Journal of Personality and Social Psychology* 1983; Vol. 44: 127-139.

Schable B, Diaz T, Chu Y & al. Who are the primary caretakers of children born to HIV-infected mothers? Results from a multistate surveillance project. *Pediatrics.* Centre for Disease Control and Prevention. Atlanta, 1995; Vol. 95(4): 511-515.

Seeley J, Kajura E, Bachengana C, Okongo M, Wagner U. & Mulder D. The extended family and support for people with AIDS in a rural population in south west Uganda: a safety net with holes? *AIDS Care* 1993; Vol. 5(1): 117-122.

Semlyen et al. Aspects of caregiver distress after severe head injury. *Journal of Neurologic Rehabilitation* 1998; Vol. 12: 53-68.

Shawky A. Social work education in Africa. *International Social Work* 1972, Vol. 15: 4-5.

Stansfeld SA. Social support and social cohesion in: Marmot M & Wilkinson G. (Eds). *Social determinants of health.* Oxford University Press, Oxford, 2000, 155-178.

Statistics Canada, Health Statistics Division. *National Health Promotion Survey.* General Report, Ottawa; 1996.

Statistics Canada, Health Statistics Division. *National Population Health Survey.* General Report, Ottawa; 1998.

Tambashe O. & Shapiro D. *Employment, education, and fertility behaviour: evidence from Kinshasa.* Université de Kinshasa, Kinshasa; 1991.

The 2000 World Fact Book. *http://www.odci.gov/cia/publications/factbook/index.html*

The 2002 World Fact Book. *http://www.odci.gov/cia/publications/factbook/index.html*

Tonglet R. & Hennart P. The support to the Health Zone: for a global approach of the health and development problems. *Health and Development.* CEMUBAC, Bruxelles, XCVI; 1991.

Turner HA, HAYS RB. & COATES TJ. Determinants of social support among gay men. Abstract SB380 from the *VIth International Conference on AIDS in San Francisco;* 1990.

Turner HA, Catania JA & Gagnon J. The prevalence of informal caregiving to persons with AIDS in the United States: caregiver characteristics and their implications. *Social Science and Medicine* 1994; Vol. 38: 1543-1552.

UNAIDS, *The fifth annual Conference on Social Work and HIV/AIDS.* General Report, San Francisco; 1993.

UNAIDS, Annual General Report, Geneva; 2001.

UNAIDS, Annual General Report, Geneva; 2002.

Van Dyk AC. Why me and not my neighbour? HIV/AIDS care and counselling in a traditional African context. *AIDS Care* 2001; Vol. 12(6): 52-67.

Verhagaen B. *Introduction à l'histoire immediate.* Duculot, Belgique; 1974.

Ward D& Brown MA. Labor and cost in AIDS family caregiving. *Western Journal of Nursing Research* 1994; Vol. 16: 10-22.

William DH. & Bridget M. *Deadly Legacy: US Arms to Africa and the Congo War.* Arms Trade Resource Centre, World Policy Institute, New York; 2000.

Wilson SN, Egnew RC & Geary C. Coordinating physical and behavioral healthcare services for Medicaid populations: issues and implications in integrated and carve-out systems. *Behav Healthc Tomorrow.* October 1996; Vol. 5(5): 67-71.

Wolcott DL, Namir S, Fawzy FI, Gottlieb MS & Mitsuyasu RT. Illness concerns, attitudes towards homosexuality, and social support in gay men with AIDS. *General Hospital Psychiatry* 1986, Vol. 8: 395-403.

Wolf A, Balson M, Morse E, Simon P, Gauuer R, Dralle P. & Williams M. Relationship of coping style for affective and perceived social support in asymptomatic and symptomatic HIV-infected persons: implications for clinical management. *Journal of Clinical Psychiatry* 1991; S2, 171-173.

APPENDICES

Appendix A: Approval letter (translated from the enclosed "Attestation de recherche")

Democratic Republic of Congo

City of Kinshasa

Municipality of Bumbu

Research Certificate

I, Mr Masunga Mbemba Mayor of Bumbu's Municipality, by the present authorize Mr Thomas Matukala Nkosi to do the research regarding his thesis in the entire territory of Bumbu.

His study's title is: *"Self-reported health status of informal women caregivers of AIDS patients in Kinshasa, Democratic Republic of Congo".*

The Professors Dr Lory Laing and Dr Walter Kipp of the Department of Public Health Sciences in Canada are supervising this study.

The present certificate is established to value the rights.

Done in Kinshasa, on June 06, 2002

Signed By Masunga Mbemba

Appendix B: Survey Questionnaire

Introduction

1. Hello, my name is _____ I am doing a survey (or, I am interviewing people) to learn about the health of women who are caring for a husband with AIDS in Kinshasa, Democratic Republic of Congo.

2. I would like to read to you some information that describes the study I am asking you to take part in. (Read information letter.) Do you have any questions? Do you understand what I have read to you? Would you be willing to be interviewed? If yes, it will take about one half hour for the interview, is this a good time to do it? (If yes, proceed to 3. If yes, but not a good time, make arrangements for another time.)

If no, terminate the interview.

3. I will need your permission to take part in this study. To do this I will read you this consent form and ask you to sign it if you agree at the end. Read consent form, mark answers, and get signature/thumb print at the end.

Thank you, let's begin:

4. Record sex of respondent
   1. Female
   2. Male

First all of all, I need to confirm that he is your husband. Is that true?
   1. Yes (continue)
   2. No (termination of the interview)

The questions I will be asking you are about the care and support you are providing to your (relation, name). Before I ask these questions, I would like to begin by asking a few questions your social and demographics' characteristics.

5. In which age category do you belong?
   1. 18-22 years
   2. 23-27 years
   3. 28-32 years
   4. 33-38 years
   5. 39-43 years
   6. 44 years or older
   0. Refusal

6. Do you have kid(s)? Yes No
If yes, how many? _____ whose _____ girl(s) and _____ boy(s)

7. What is your religion?
1. Catholic
2. Protestant
3. Islam
4. Kimbaguist
5. Other
6. No religion
0. Refusal

8. In which ethnic group you belong to?
1. Kongo
2. Luba
3. Kwilukwango
4. Mongo
5. Ubangi
6. Shwayili
7. Other
0. Refusal

9. What is the highest level of education you have attended or completed?
1. No schooling
2. Some Elementary
3. Completed Elementary
4. Some Secondary
5. Completed Secondary
6. Some college, technical, or nurse's training
7. Some University
8. Completed University
9. Other education or training (please specify)_____
0. Refusal

10. Are you employed?
0. Yes, full-time
1. Yes, part-time
2. On leave (e.g. pregnancy, medical, compassionate)
3. Other
4. No
5. Refusal

11. Are you…
1. Unemployed
2. Retired, or
3. A student

4. Other (please specify)_____

12. Do you own or rent your home?
1. Own
2. Rent
3. Other (please specify)_____
0. Refusal

13. Which of the following categories best reflects your total household income last year, before taxes. Was it …
1. Less than $1,000
2. Between $1,000 and $5,000
3. More than $5,000
0. Refusal

14. Do you have a:

1. bicycle	Yes	No
2. radio	Yes	No
3. car	Yes	No
4. TV	Yes	No
5. Motorcycle	Yes	No

15. Does your home have

1. Electricity	Yes	No
2. Water	Yes	No

Now, I would like to ask a few questions about your husband.

16. And he is living
1. With you
2. Independently in his own home (Go to the question 18)
3. In hospital (Go to the question 18)
4. In Home-based care program centre (Go to the question 18)
5. Others (specify)_____
0. Refusal

17. How long has he lived with you or where he is?
1. Less than three months (termination of the interview)
2. Between three and six months (termination of the interview)
3. More than six months

18. Even though he not living with you, are you still his main caregiver?
1. Yes
2. No (termination of the interview)

19. Do your husband:
    1. Stay in bed most the time
    2. Lay and lay up in bed
    3. Most the time up
    0. Refusal

In this survey, a caregiver is someone who provides care or support to her husband who is suffering from AIDS. Care includes things like housework, bathing, dressing or helping with medication. Support includes things like helping with an emotional problem, arranging for services, helping him find suitable activities, or doing things together.

It is time to talk about the care and support you are providing to your husband and its implications.

20. How long have you been providing care or support to your husband?
    1. Less than six months (termination of the interview)
    2. More than six months

21. For each situation, please tell me if you have provided this type of care or support to your husband in the last six months

	Yes	No	Refusal
Helping him with buying, cooking or eating food	1	2	0
Helping him bathe or use the toilet	1	2	0
Helping with dressing, combing hair or brushing teeth	1	2	0
Helping with getting out of bed or a chair, or walking	1	2	0
Helping him with medications	1	2	0
Monitoring his health	1	2	0
Helping with rehabilitation or re-learning	1	2	0
Communicating with professionals/health care providers	1	2	0
Arranging for someone to stay with him when you cannot	1	2	0
Helping him deal with his emotions	1	2	0
Looking for services or resources to help him	1	2	0

Others (Specify)_____

22. Is there anything that eases the burden of caregiving?
    1. Yes
    2. No
    0. Refusal

If yes, what is it?

_____

_____

_____

23. Has being a caregiver to your husband become difficult in some ways?
    1. Yes How: _____

2. No
0. Refusal

24. Compared to other people of your age, would you say in general your health is …

1. Excellent
2. Very Good
3. Good
4. Fair
5. Poor
6. Don't know (volunteered)
0. Refusal

25. Would you describe your life as:

1. Very stressful
2. Fairly stressful
3. Not very stressful
4. Not stressful
0. Refusal

26. Would you describe yourself as being usually:

1. Happy and interested in life?
2. Somewhat happy?
3. Somewhat unhappy?
4. Unhappy with little interest in life?
5. So unhappy that life is not worthwhile?
0. Refusal

27. How often do you feel you had support from others to make sure your basic needs were met? Would you say you had support…

1. Never or almost never
2. Seldom
3. Sometimes
4. Often
5. Almost always
6. Don't know
0. Refusal

28. Who do you feel has been the greatest support to you in making sure your basic needs have been met?

Do not record proper names; instead record relationship of person to caregiver (e.g. my father-in-law)
Survivor = 77
Don't know = 88
Refusal = 99

---

29. Do you appreciate the help of home care staffs? Yes No
If yes, how often do they come or do they help?

_____

30. Do you worry what your friends or neighbours would do if they knew your Husband had AIDS?
    1. Yes, a lot
    2. Yes, somewhat
    3. No
    0. Refusal

31. Do you feel ostracized by your

1. relatives	Yes	No
2. neighbours	Yes	No
3. friends	Yes	No
4. others	Yes	No

32. Do you find family finances are limited by having to pay for things that your husband needs for his care?
    1. Yes, a lot
    2. Yes, somewhat
    3. No
    0. Refusal

33. In the past 12 months, did you have a health problem for which you saw a doctor or a nurse or other health care worker?
    1. Yes What kinds of health problem? _____
    2. No

34. In the past 12 months, did you have a health problem for which you did not consult a medical worker?
    1. Yes What kinds of health problem? _____
    2. No

35. In the past 12 months, did you get treatment?
    1. Yes, could you afford drugs? Yes No
    2. No

36. In the last 12 months and because you are a caregiver, were you limited in your ability to do things like:

1. participating in any social activities?	Yes	No
2. being able to manage your children?	Yes	No
3. having time to do your own things?	Yes	No

37. Since you became a caregiver for your husband, have you had any health problems?

1. Yes Specify: _____
2. No

38. How far is the home care center away from your home and how do you get there?

_____
_____

39. What would make your life as a caregiver easier?

Don't know = 88
Refusal 99

_____
_____
_____

40. Dou you have any comments you would like to make about your role as a caregiver, or comments you would like to make about this survey?

_____
_____
_____

We have reached the end of our questions and I would like to thank you very much for taking the time to do this interview.

This section is to be completed by Interviewer: results to be aggregated separately from main interview.

1. How would you rate the respondent's comprehension of the questions?

1. Excellent
2. Very good
3. Good
4. Fair
5. Poor

2. How would you rate the respondent's interest in the survey?

1. Excellent
2. Very good
3. Good
4. Fair
5. Poor

3. How would you rate the respondent's openness, frankness?

1. Excellent
2. Very good

3. Good
4. Fair
5. Poor

4. How would you rate the overall quality of the interview?
1. Excellent
2. Very good
3. Good
4. Fair
5. Poor

Do you have any comments about the interview?

_____

_____

_____

1. Please record the length of the interview in minutes. _____

2. PLEASE GO THROUGH THE QUESTIONNAIRE AGAIN FOR YOUR FINAL EDIT RECORDING IT AS A "COMPLETED INTERVIEW".

Appendix C: Information letter (#1) about the survey for caregivers

Project title: *Self-reported health status of informal women caregivers of AIDS patients in Kinshasa, Democratic Republic of Congo*

Principal Investigator: Thomas Matukala Nkosi, Public Health Sciences, University of Alberta, Edmonton, Canada

Date: September 2002

Dear caregiver:

You are being asked to participate in a study that is looking at the problems that caregivers of AIDS patients face in their care for their loved ones. The study is being conducted by Thomas Matukala Nkosi, Graduate Student in the Public Health Sciences Department, University of Alberta, Edmonton, Canada.

Purpose of the study:

The purpose of this study is to assess if the additional caregiving burden imposed on the women who care for HIV/AIDS patients in Democratic Republic of Congo has a negative impact on the women's health.

Background of the study:

The home-based care program is part of the Kinshasa HIV/AIDS program and began in 1986. You have had visits from the home-based care nurse to help with the medical care for your patient. The Congolese Government and the Health Minister are making plans to include services in the home-based care program that would meet the needs of the informal caregivers. In order to get information for the development of this program, we need information on the problems and constraints you as an informal caregiver face every day with the care of your patient. The information you provide to the study team may help to make this program more beneficial to you.

Procedures:

On _____ (date & time) at _____ (place), a trained interviewer will ask you questions from a questionnaire. The questions will be about your experiences and problems regarding the care of your AIDS patient at home and how you deal with it. Answering the questions from the questionnaire will take you 1 hour. Interviews will take place where you choose. If you need some help with this choice, the interviewer will assist you. The interviews will be audio taped. The

interviewer will also use information gained through observations. The information gathered for this study may be looked at again in the future to help us answer other study questions. If so, the Ethics Board will first review the study to ensure the information is ethically used. You will receive C$5 for your transportation costs.

Possible benefits:

At the end of the questionnaire, the interviewer will ask you if you have any questions about the study or about the home-based care program. If the interviewer cannot answer the question, she will refer you to someone else who can answer your question.

The information from this study may help the Health Minister improve the home-based care program in the future. This may mean that many women in Bumbu and in Kinshasa/Congo will benefit from this study.

Possible harms:

There are no expected harms to taking part in this study. We do not want you to feel any stress or pressure about sharing information with us. If you feel badly while you are participating, please remember that you can leave at any time and your future home-based care will not be compromised in any way. If you feel badly after you have shared information with us, and you feel distress, please tell us. In case you are not able to contact anyone on the research team, please seek help in the home-based care program centre. If you want, the investigator can also make arrangements for you to receive help from trained counsellors. The research assistant and myself are available at the home-based care program centre to answer any questions or receive any concerns you may have about your participation in the study and arrange help if you need it. If you want to talk to someone neutral, you can contact Prof. Bernard Lututala Mumpasi, the economics faculty Vice-Dean of Research and former Head of the Demography Department, University of Kinshasa, B.P. 176, Kinshasa XI.

Confidentiality and voluntary participation:

All records will be kept private. Your name will not appear with your answers. The questionnaires will be kept in a secure area. Only the research team will have access to the information you give.

We will report what we learn from this study to the home-based care program in Bumbu and the Ministry of Health in Kinshasa. However, we will not tell them specifically what any individual has said. Instead, we will tell them about the comments of the whole group of participants in general. We will never use your name. Nobody will be able to trace responses back to you.

The information collected in this study will be kept for at least five years after the study is completed. It will be kept in a secure place at the University of Alberta, Edmonton, Alberta, Canada. Only the research team will have access to this stored information. If we plan to use this information for further study, we will obtain ethics approval first.

You are not required to participate in this study. You do not have to answer any question that you do not want to. You can also leave the study anytime you want without fear that anything bad will happen.

For more information on the study:

If you have any concerns about this study or would like to have more information, please contact Prof. Bernard Lututala Mumpasi, the economics faculty Vice-Dean of Research and former Head of the Demography Department, at the University of Kinshasa.

Your consent and legal rights:

Your signature on the next page means that you understand the information in this letter. It also means that you agree to participate in this study.

Please keep these pages in case you need them in future.

Initials caregiver: _____

Initials investigator: _____

Date: _____

Appendix C: Information letter (#2) about the focus group for caregivers

Project title: *Self-reported health status of informal women caregivers of AIDS patients in Kinshasa, Democratic Republic of Congo*

Principal Investigator: Thomas Matukala Nkosi, Public Health Sciences,
University of Alberta, Edmonton, Canada

Date: September 2002

Dear caregiver:

You are being asked to participate in a study that is looking at the problems that caregivers of AIDS patients face in their care for their loved ones. The study is being conducted by Thomas Matukala Nkosi, Graduate Student in the Public Health Sciences Department, University of Alberta, Edmonton, Canada.

Purpose of the study:

The purpose of this study is to assess if the additional caregiving burden imposed on the women who care for HIV/AIDS patients in Democratic Republic of Congo has a negative impact on the women's health.

Background of the study:

The home-based care program is part of the Kinshasa HIV/AIDS program and began in 1986. You have had visits from the home-based care nurse to help with the medical care for your patient. The Congolese Government and the Health Minister are making plans to include services in the home-based care program that would meet the needs of the informal caregivers. In order to get information for the development of this program, we need information on the problems and constraints you as an informal caregiver face every day with the care of your patient. The information you provide to the study team **may** help to make this program more beneficial to you.

Procedures:

On _____ (date & time) at _____ (place), you will be asked to participate in a group discussion. Discussion topics will be about your experiences and problems regarding the care of your AIDS patient at home and how

you deal with it. The group discussions will last for 11/2 hours. Discussions will take place where you choose. If you need some help with this choice, a team research member will assist you. The discussion will be audio taped. The interviewer will also use information gained through observations. The information gathered for this study may be looked at again in the future to help us answer other study questions. If so, the Ethics Board will first review the study to ensure the information is ethically used. You will receive C$5 for your transportation costs.

Possible benefits:

At the end of the discussion, a research team member will ask you if you have any questions about the study or about the home-based care program. If s/he cannot answer the question, s/he will refer you to someone else who can answer your question.

The information from this study may help the Health Minister improve the home-based care program in the future. This may mean that many women in Bumbu and in Kinshasa/Congo will benefit from this study.

Possible harms:

There are no expected harms to taking part in this study. We do not want you to feel any stress or pressure about sharing information with us. If you feel badly while you are participating, please remember that you can leave at any time and your future home-based care will not be compromised in any way. If you feel badly after you have shared information with us, and you feel distress, please tell us. In case you are not able to contact anyone on the research team, please seek help in the home-based care program center. If you want, the investigator can also make arrangements for you to receive help from trained counselors. The research assistant and myself are available at the home-based care program center to answer any questions or receive any concerns you may have about your participation in the study and arrange help if you need it. If you want to talk to someone neutral, you can contact Prof. Bernard Lututala Mumpasi, the economics faculty Vice-Dean of Research and former Head of the Demography Department, University of Kinshasa, B.P. 176, Kinshasa XI.

Confidentiality and voluntary participation:

All records will be kept private. Your name will not appear with your answers. The information from the discussions will be kept in a secure area. Only the research team will have access to the information you give. Each participant will be encouraged not to release information from the discussion to people outside of the study. So, before the group discussion begins, a research team member will remind the group that what is said needs to remain confidential. If there is something you would not like to be discussed or known, please do not feel any pressure to share it with the group.

We will report what we learn from this study to the home-based care program in Bumbu and the Ministry of Health in Kinshasa. However, we will not tell them specifically what any individual has said. Instead, we will tell them about the comments of the whole group of participants in general. We will never use your name. Nobody will be able to trace responses back to you.

The information collected in this study will be kept for at least five years after the study is completed. It will be kept in a secure place at the University of Alberta, Edmonton, Alberta, Canada. Only the research team will have access to this stored information. If we plan to use this information for further study, we will obtain ethics approval first.

You are not required to participate in this study. You do not have to answer any question that you do not want to. You can also leave the study anytime you want without fear that anything bad will happen.

For more information on the study:

If you have any concerns about this study or would like to have more information, please contact Prof. Bernard Lututala Mumpasi, the economics faculty Vice-Dean of Research and former Head of the Demography Department, at the University of Kinshasa.

Your consent and legal rights:

Your signature on the next page means that you understand the information in this letter. It also means that you agree to participate in this study.

Please keep these pages in case you need them in future.

Initials caregiver: _____

Initials investigator: _____

Date: _____

Appendix C: Information letter (#3) about the focus group for Sacome+ staff

Project title: *Self-reported health status of informal women caregivers of AIDS patients in Kinshasa, Democratic Republic of Congo*

Principal Investigator: Thomas Matukala Nkosi, Public Health Sciences,
University of Alberta, Edmonton, Canada

Date: September 2002

Dear Sacome+ staff:

You are being asked to participate in a study that is looking at the problems that caregivers of AIDS patients face in their care for their loved ones. The study is being conducted by Thomas Matukala Nkosi, Graduate Student in the Public Health Sciences Department, University of Alberta, Edmonton, Canada.

Purpose of the study:

The purpose of this study is to assess if the additional caregiving burden imposed on the women who care for HIV/AIDS patients in Democratic Republic of Congo has a negative impact on the women's health.

Background of the study:

The home-based care program is part of the Kinshasa HIV/AIDS program and began in 1986. The Congolese Government and the Health Minister are making plans to include services in the home-based care program that would meet the needs of the informal caregivers. In order to get information for the development of this program, we need information on the problems and constraints that may affect this program. The information you provide to the study team may help to improve this program.

Procedures:

On _____ (date & time) at _____ (place), you will be asked to participate in a group discussion. Discussion topics will be about your experiences and problems as a health worker of the AIDS patient at home-based program and how you deal with it. The group discussions will last for 11/2 hours.

Discussions will take place where you choose. If you need some help with this choice, a team research member will assist you. The discussion will be audio taped. The interviewer will also use information gained through observations. The information gathered for this study may be looked at again in the future to help us answer other study questions. If so, the Ethics Board will first review the study to ensure the information is ethically used. You will receive C$5 for your transportation costs.

Possible benefits:

At the end of the discussion, a research team member will ask you if you have any questions about the study or about the home-based care program. If s/he cannot answer the question, s/he will refer you to someone else who can answer your question.

The information from this study may help the Health Minister improve the home-based care program in the future. This may mean that many women in Bumbu and in Kinshasa/Congo will benefit from this study.

Possible harms:

There are no expected harms to taking part in this study. We do not want you to feel any stress or pressure about sharing information with us. If you feel badly while you are participating, please remember that you can leave at any time. If you feel badly after you have shared information with us, and you feel distress, please tell us. In case you are not able to contact anyone on the research team, please seek help in the home-based care program center. If you want, the investigator can also make arrangements for you to receive help from trained counselors. The research assistant and myself are available at the home-based care program center to answer any questions or receive any concerns you may have about your participation in the study and arrange help if you need it. If you want to talk to someone neutral, you can contact Prof. Bernard Lututala Mumpasi, the economics faculty Vice-Dean of Research and former Head of the Demography Department, University of Kinshasa, B.P. 176, Kinshasa XI.

Confidentiality and voluntary participation:

All records will be kept private. Your name will not appear with your answers. The information from the discussions will be kept in a secure area. Only the research team will have access to the information you give. Each participant will be encouraged not to release information from the discussion to people outside of the study. So, before the group discussion begins, a research team member will remind the group that what is said needs to remain confidential. If there is something you would not like to be discussed or known, please do not feel any pressure to share it with the group.

We will report what we learn from this study to the home-based care program in Bumbu and the Ministry of Health in Kinshasa. However, we will not tell them specifically what any individual has said. Instead, we will tell them about the comments of the whole group of participants in general. We will never use your name. Nobody will be able to trace responses back to you.

The information collected in this study will be kept for at least five years after the study is completed. It will be kept in a secure place at the University of Alberta, Edmonton, Alberta, Canada. Only the research team will have access to this stored information. If we plan to use this information for further study, we will obtain ethics approval first.

You are not required to participate in this study. You do not have to answer any question that you do not want to. You can also leave the study anytime you want without fear that anything bad will happen.

For more information on the study:

If you have any concerns about this study or would like to have more information, please contact Prof. Bernard Lututala Mumpasi, the economics faculty Vice-Dean of Research and former Head of the Demography Department, at the University of Kinshasa.

Your consent and legal rights:

Your signature on the next page means that you understand the information in this letter. It also means that you agree to participate in this study.

Please keep these pages in case you need them in future.

Initials caregiver: _____

Initials investigator: _____

Date: _____

Appendix C: Information letter (#4) about the focus group for Key informants

Project title: *Self-reported health status of informal women caregivers of AIDS patients in Kinshasa, Democratic Republic of Congo*

Principal Investigator: Thomas Matukala Nkosi, Public Health Sciences,
University of Alberta, Edmonton, Canada

Date: June 2002

Dear Key informants:

You are being asked to participate in a study that is looking at the problems that caregivers of AIDS patients face in their care for their loved ones. The study is being conducted by Thomas Matukala Nkosi, Graduate Student in the Public Health Sciences Department, University of Alberta, Edmonton, Canada.

Purpose of the study:

The purpose of this study is to assess if the additional caregiving burden imposed on the women who care for HIV/AIDS patients in Democratic Republic of Congo has a negative impact on the women's health.

Background of the study:

The home-based care program is part of the Kinshasa HIV/AIDS program and began in 1986. The Congolese Government and the Health Minister are making plans to include services in the home-based care program that would meet the needs of the informal caregivers. In order to get information for the development of this program, we need information on the problems and constraints that may affect this program. The information you provide to the study team may help to improve this program.

Procedures:

On _____ (date & time) at _____ (place), you will be asked to participate in a group discussion. Discussion topics will be on your experiences and problems as a Bumbu Municipality Council member about the AIDS patient at home-based program and how you deal with it. The group discussions will last

for 11/2 hours. Discussions will take place where you choose. If you need some help with this choice, a team research member will assist you. The discussion will be audio taped. The interviewer will also use information gained through observations. The information gathered for this study may be looked at again in the future to help us answer other study questions. If so, the Ethics Board will first review the study to ensure the information is ethically used. You will receive C$5 for your transportation costs.

Possible benefits:

At the end of the discussion, a research team member will ask you if you have any questions about the study or about the home-based care program. If s/he cannot answer the question, s/he will refer you to someone else who can answer your question.

The information from this study may help the Health Minister improve the home-based care program in the future. This may mean that many women in Bumbu and in Kinshasa/Congo will benefit from this study.

Possible harms:

There are no expected harms to taking part in this study. We do not want you to feel any stress or pressure about sharing information with us. If you feel badly while you are participating, please remember that you can leave at any time. If you feel badly after you have shared information with us, and you feel distress, please tell us. In case you are not able to contact anyone on the research team, please seek help in the home-based care program center. If you want, the investigator can also make arrangements for you to receive help from trained counselors. The research assistant and myself are available at the home-based care program center to answer any questions or receive any concerns you may have about your participation in the study and arrange help if you need it. If you want to talk to someone neutral, you can contact Prof. Bernard Lututala Mumpasi, the economics faculty Vice-Dean of Research and former Head of the Demography Department, University of Kinshasa, B.P. 176, Kinshasa XI.

Confidentiality and voluntary participation:

All records will be kept private. Your name will not appear with your answers. The information from the discussions will be kept in a secure area. Only the research team will have access to the information you give. Each participant will be encouraged not to release information from the discussion to people outside of the study. So, before the group discussion begins, a research team member will remind the group that what is said needs to remain confidential. If there is something you would not like to be discussed or known, please do not feel any pressure to share it with the group.

We will report what we learn from this study to the home-based care program in Bumbu and the Ministry of Health in Kinshasa. However, we will not tell them specifically what any individual has said. Instead, we will tell them about the comments of the whole group of participants in general. We will never use your name. Nobody will be able to trace responses back to you.

The information collected in this study will be kept for at least five years after the study is completed. It will be kept in a secure place at the University of Alberta, Edmonton, Alberta, Canada. Only the research team will have access to this stored information. If we plan to use this information for further study, we will obtain ethics approval first.

You are not required to participate in this study. You do not have to answer any question that you do not want to. You can also leave the study anytime you want without fear that anything bad will happen.

For more information on the study:

If you have any concerns about this study or would like to have more information, please contact Prof. Bernard Lututala Mumpasi, the economics faculty Vice-Dean of Research and former Head of the Demography Department, at the University of Kinshasa.

Your consent and legal rights:

Your signature on the next page means that you understand the information in this letter. It also means that you agree to participate in this study.

Please keep these pages in case you need them in future.

Initials caregiver: _____

Initials investigator: _____

Date: _____

Appendix D: Consent form (#1) for caregivers

Project title: *Self-reported health status of informal women caregivers of AIDS patients in Kinshasa, Democratic Republic of Congo*

Principal Investigator: Thomas Matukala Nkosi, Public Health Sciences, University of Alberta, Edmonton, Canada

Do you understand that you have been asked to participate in a research study?	Yes	No
Have you read and received a copy of the attached information letter?	Yes	No
Do you understand the benefits and risks involved in taking part in this research study?	Yes	No
Have you had an opportunity to ask questions and discuss the study?	Yes	No
Do you understand that you are free to participate or withdraw from the study at any time? You do not have to give a reason. This will not affect the future health of you and your family and/or health services provided to your family.	Yes	No
Has the issue of confidentiality been explained to you? Do you understand who will have access to your records?	Yes	No

This study was explained to me by:

I agree to take part in this study

----------	----------	----------
Signature of research participant	Date	Witness
----------		----------
Printed name		Printed name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

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Signature of investigator or Designee	Date

Appendix D: Consent form (#2) for Sacome+ staff

Project title: *Self-reported health status of informal women caregivers of AIDS patients in Kinshasa, Democratic Republic of Congo*

Principal Investigator: Thomas Matukala Nkosi, Public Health Sciences, University of Alberta, Edmonton, Canada

Do you understand that you have been asked to participate in a research study?	Yes	No
Have you read and received a copy of the attached information letter?	Yes	No
Do you understand the benefits and risks involved in taking part in this research study?	Yes	No
Have you had an opportunity to ask questions and discuss the study?	Yes	No
Do you understand that you are free to participate or withdraw from the study at any time? You do not have to give a reason. This will not affect your job.	Yes	No
Has the issue of confidentiality been explained to you? Do you understand who will have access to your records?	Yes	No

This study was explained to me by:

I agree to take part in this study

----------	----------	----------
Signature of research participant	Date	Witness
----------		----------
Printed name		Printed name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

----------	----------
Signature of investigator or Designee	Date

Appendix D: Consent form (#3) for Key informants

Project title: *Self-reported health status of informal women caregivers of AIDS patients in Kinshasa, Democratic Republic of Congo*

Principal Investigator: Thomas Matukala Nkosi, Public Health Sciences, University of Alberta, Edmonton, Canada

Do you understand that you have been asked to participate in a research study?	Yes	No
Have you read and received a copy of the attached information letter?	Yes	No
Do you understand the benefits and risks involved in taking part in this research study?	Yes	No
Have you had an opportunity to ask questions and discuss the study?	Yes	No
Do you understand that you are free to participate or withdraw from the study at any time? You do not have to give a reason.	Yes	No
Has the issue of confidentiality been explained to you? Do you understand who will have access to your records?	Yes	No

This study was explained to me by:

I agree to take part in this study

----------	----------	----------
Signature of research participant	Date	Witness
----------		----------
Printed name		Printed name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

----------	----------
Signature of investigator or Designee	Date

Appendix E: Question guide for the Key informants

1. Could you please tell me about your experience as _____ at the home care program for HIV/AIDS patients from the zone of Bumbu?

2. In Your opinion, there is a need for extending the existing services at the home care? Why?

3. The home care offers a lot of services. Which one(s) is (or are) not appropriate for the patients and their families? Please explain your choice.

Appendix F: Guideline for the semi-structured interviews with caregivers

1. Tell me how you came to be a caregiver for _____?

   a. What was it like when s/he came home or at the hospital/clinic?
   b. How did your life change?
   c. How did that change the rest of your family?

2. Thinking about your life over the last _____ months/years, what is the best thing that has happened to you? It may be something related to your role as a caregiver, or it may not.

   a. When have you felt best or happiest?
   b. Why do you think that was the best thing that happened / that was the happiest time for you?

3. Thinking about that same period of time, when did you face most difficult challenge? Again, it might be something related to your role as a caregiver, or it may not.

4. How did you deal with that difficult challenge?

   a. What did you do to help yourself to get through that?
   b. Did you receive any help from anybody or any institution and if yes what kind of help was that?

5. What advice would you have for someone who is just starting to be a caregiver for a husband with HIV/AIDS?